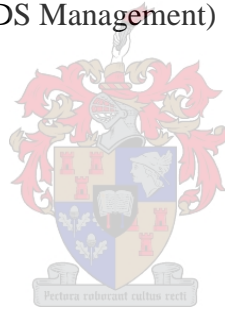


Factors that contribute to HIV-related stigma and discrimination within the Christian faith community: a survey of the Christ Embassy Church in Windhoek

Nomusa Senzanje

Assignment presented in partial fulfillment of the requirements for the degree of Master of Philosophy (HIV and AIDS Management) at Stellenbosch University



Africa Centre for HIV/AIDS Management
Faculty of Economic and Management Sciences

Supervisor: Dr Thozamile Qubuda

March 2011

Declaration

By submitting this assignment electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that reproduction and publication thereof by Stellenbosch University will not infringe any third party rights and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

Signed

A handwritten signature in blue ink, appearing to be 'M. B.', is displayed on a light blue rectangular background.

Date: March 2011

Acknowledgements

I give gratitude to God for granting me wisdom and the ability to accomplish this study in spite of all the constraints that were encountered. I would also like to express my sincere gratitude to the following people:

- My supervisor, Dr Thozamile Qubuda for his guidance throughout the research.
- Pastor Dillan for granting me approval to conduct this study.
- Brother Sheya who helped me to contact the cell leaders.
- Members of the Christ Embassy Church who participated in the survey.
- To my husband and children for their support, understanding and encouragement that made completion of this study possible.

Abstract

This study investigated the problem of HIV/AIDS stigma and discrimination in faith communities and explored the contributing factors in order to inform effective intervention strategies. The non-experimental quantitative research method using questionnaires was used to collect data. The study surveyed a total of 60 respondents who belonged to the Christ Embassy Church in Windhoek. The survey included several aspects of stigma, such as: negative attitudes and values towards people living with HIV/AIDS (PLHA); perceived risk of HIV infection due to casual contact with PLHA; disclosure of HIV status; social distancing from PLHA and sources of information on HIV/AIDS. Data was analyzed using Microsoft Excel 2007.

Results showed that knowledge of HIV/AIDS amongst respondents was considerably high. However, no significant relationship was found between knowledge and stigma. The findings established the existence of personal stigma which was manifested in the fears of casual contact and stigmatizing values exhibited by a significant number of respondents. The respondents held highly judgmental beliefs, shame and blame for PLHA. Although incidences of enacted stigma were generally low, it was apparent that lack of space for HIV/AIDS discussions, lack of disclosure, lack of dissemination of HIV/AIDS information and deeply rooted religious beliefs played a major role in perpetuating stigma in the Church. Personal stigma was defined as the individual's own attitude towards PLHA and enacted stigma were the actual acts of discrimination.

Opsomming

Hierdie studie ondersoek die probleem van MIV/VIGS verwante stigma en diskriminasie in die geloofsgemeenskappe en verken die bydraende faktore ten einde effektiewe intervensie strategieë te lig. 'n Nie-eksperimentele kwantitatiewe navorsingsmetode is vir die studie gebruik waardeur vraelyste gebruik is om data in te samel. Die studie ondersoek 'n totaal van 60 respondente wat behoort aan die Christus Ambassade Kerk in Windhoek. Die opname sluit in verskeie aspekte rondom stigma, soos: negatiewe houdings en waardes teenoor mense wat met MIV/VIGS lewe; ervaar risiko van MIV-infeksie as gevolg van toevallige kontak met mense met MIV/VIGS; bekendmaking van MIV-status, sosiale afstand van mense met MIV/VIGS en bronne van inligting oor MIV/VIGS. Data is ontleed met behulp van Microsoft Excel 2007.

Resultate dui daarop dat kennis van MIV/VIGS onder respondente aansienlik hoog is. Daar is egter geen beduidende verband gevind tussen kennis en stigma nie. Hoewel gevalle van stigma voorgekom het was dit oor die algemeen laag. Dit is duidelik dat daar 'n gebrek is aan ruimte vir MIV/VIGS besprekings sowel as bekendmaking en verspreiding van MIV/VIGS inligting. Diep gewortelde godsdienstige oortuigings speel 'n belangrike rol in die uitwissing van stigma in die kerk. Persoonlike stigma is gedefinieer as die individu se eie houding teenoor mense met MIV/VIGS.

Table of Contents

Chapter 1	Introduction	
1.1	Background	1
1.2	Research Problem	4
1.3	Significance of the Study	6
1.4	Research Question	6
1.5	Aim	7
1.6	Objectives	7
1.7	Outline of Chapters	7
1.8	Summary	8
Chapter 2	Literature Review	
2.1	Introduction	9
2.2	Definition of Stigma and Discrimination	9
2.3	Forms of Stigma	11
2.4	Expressions of Stigma and Discrimination in the Church	13
2.5	Causes of Stigma and Discrimination in the Church	15
2.6	Implications for Prevention	22
2.7	Addressing Stigma in the Church	23
2.8	Gaps in the Knowledge	25
2.9	Summary	25
Chapter 3	Methodology	
3.1	Introduction	26
3.2	Paradigm	26
3.3	Research Design	26
3.4	Target Population	26
3.5	Sampling	27
3.6	Measuring Instrument	27
3.7	Data Collection	28
3.8	Data Analysis	29
3.9	Ethical Procedures	29

Chapter 4	Data Analysis and Discussion of Findings	
4.1	Introduction	31
4.2	Socio-Demographic Data	31
4.3	Knowledge of HIV/AIDS	33
4.4	Personal Stigma Indicators	35
4.5	Enacted Stigma	40
4.6	Disclosure	40
4.7	Sources of Information	42
4.8	Discussion of Findings	45
Chapter 5	Conclusion and Recommendations	
5.1	Conclusion	51
5.2	Recommendations	51
5.3	Limitations of Research	53
5.4	Areas of Further Research	53
References	54
Appendix 1- Questionnaire	61
Appendix 2- Consent Form	65
Appendix 3- Letter of Approval	68

Chapter 1: Introduction

1.1 Background

In 1987, the late John Mann, the director of the World Health Organization (WHO) Global Programme on AIDS, identified three phases of the HIV/AIDS epidemic. The first is the epidemic of HIV infection, which enters a community silently and unnoticed. Next follows the epidemic AIDS, which follows when HIV triggers life-threatening infections. Finally, there is a third epidemic – the epidemic of stigma, discrimination, blame and collective denial – that makes it so difficult to effectively tackle the first two (Parker & Aggleton, 20002). UNAIDS (2005), defines stigma as the branding or labelling of a person or a group of persons as being unworthy of inclusion in human community, resulting in discrimination and ostracization. Whereas Nyblade and MacQuarrie (2006) define discrimination as differential or unfair treatment based on HIV status or association with someone who is living with HIV/AIDS.

Intense negative feelings and actions directed towards People Living with HIV/AIDS (PLHA) have characterized the HIV/AIDS epidemic since its inception. PLHA have been denied employment, fired from their jobs, experienced mental and physical abuse, and ostracized from their families and communities (Herek & Glunt, 1988). Such treatment can be attributed to the fact that PLHA are believed to have done something wrong to acquire HIV infection. According to Parker and Aggleton (2003), these “wrongdoings” are illegal and socially unacceptable activities or behaviour such as injecting drugs, prostitution or infidelity. HIV is also associated with fear and misconceptions, people often suspect that individuals with HIV or AIDS pose a threat to the community at large. This misconception is not limited to the general population, but has extended to the faith community.

Therefore the global fight against HIV/AIDS has taken a new twist in recent times with reports of the escalation of the epidemic accompanied by accusations that the faith community contributes to the spread of the disease rather than its prevention (Speicher & Wilson, 2007). Not much work has been done in Namibia to provide evidence of the existence of HIV/AIDS stigma and discrimination in faith communities. Therefore the present study investigates this problem and explores the contributing factors in order to inform effective intervention strategies. According to Parker and Aggleton (2003), research

on interventions in relation to stigmatization has shown to yield very few results in changing stigmatizing attitudes, whether through empathy inducement or other psychological theories on the part of dominant sectors of society. This may be due to the fact that considerably less attention has been devoted to understand the underlying causes of stigma and discrimination; hence intervention strategies have proved less effective.

Stigmatization and discrimination which operate at the level of human community, local culture, and the way in which day-to-day life of the worshipping, praying and believing, seem to weaken the position of the faith community in the fight against the HIV/AIDS epidemic (MIAA, 2006). In cognizance of this situation, a group of African church leaders met in November 2001, in Nairobi, to draw up an ecumenical plan of action for responding to the HIV/AIDS epidemic. Their conclusion was that the most powerful contribution that churches can make to combating HIV transmission is the eradication of stigma and discrimination (GAIA, 2005).

HIV and AIDS in Namibia

Vast differences in HIV infection rates occur in Namibia with Caprivi the region most affected with almost 43 percent of the region's adult population living with HIV. Although the absolute numbers of people affected may not be as great as in other countries, the impact of HIV/AIDS on a sparsely populated country of 1.8 million people with a long history of colonial domination and a critically thin skills base could be devastating (UNAIDS, 2006). The relatively stable trend since the mid-1990s in HIV prevalence among young pregnant women (15-24 years), and the rising trend among those in their 30s suggests that prevention efforts need to be improved (Ministry of Health and Social Services, 2007), although evidence suggests that the prevalence rate, estimated at 20 percent (UNAIDS, 2007) may be starting to decline in Namibia, stigma and discrimination poses significant challenges, which may further see the spread of HIV infection. Studies have found out that general awareness of HIV/AIDS is relatively high in Namibia, for example, among young people ages 15-24, 82 percent of young women and 87 percent of young men knew that a healthy looking person could be infected with HIV. However, significant stigma and misconceptions, about HIV disease remain (MOHSS, 2005), despite the withdrawal of the Sterilization and Termination of Pregnancy Bill of 1996 after public outcry spearheaded by church denominations in the country against the Bill in 1999 (ICW, 2006). Three Namibian women who allege that state

hospitals sterilized them without their consent, denying their right to motherhood, because they were diagnosed HIV positive are suing the Ministry of Health and Social Services for N\$1 million each (The Namibian, May 28 2010). Such activities violate numerous rights guaranteed under the Namibian constitution and Namibia's obligations under International laws (ICW, 2009).

The response of Churches to HIV and AIDS

The church can be defined as the body of Christ and a healing community. In most cases the church considers those it serves as sinners who need to be preached at and converted to the faith (Xapile, 2009). Sub-Saharan Africa is the most Christian of all continents after Latin America. Roman Catholic and many Protestant Churches were founded there in the era of colonialism and missionary work. While these missions have served some colonial purposes, they have also provided the local community with a church, a school and health facilities (KIT, 2004). AIDS has revealed such intense discord within and among churches as well as at all levels of society. While treatment, care and support are often integral parts of church life and action, churches too often are afraid to offer visible and strong support for effective methods of HIV prevention. Such actions should be taken with sensitivity to different beliefs and traditions, but open to challenging myths and misconceptions, practices and traditions that increase both the spread of HIV and the perpetuation of stigma (Speicher & Wilson, 2007).

According to a PACANet study conducted in 2003, the churches with the largest faith-based responses to HIV/AIDS are the so-called mainline churches – The Anglicans, the Lutherans, and the Roman Catholics, which have a considerable membership of over 62 percent of the Namibian population. Other churches which include the African Methodist Episcopal Church (AMEC), the Rhenish Church, the Methodist Church, the Uniting Reformed Church, the Dutch Reformed Church and the Congregational Church are very small in number. More and more of the Pentecostal and evangelical churches have recently become more involved in both prevention and care activities. The Council of Churches is aware of these differences, and sees a role for itself not only in supporting those well-established church interventions when necessary, but also in encouraging and assisting the smaller churches to establish their own or combine with others to establish an HIV/AIDS response (PACANet 2003). The

Christ Embassy Church in Windhoek was selected for the study since it has not established faith-based responses to HIV/AIDS.

The churches in Namibia are involved in a variety of HIV/AIDS activities, and the table below illustrates the HIV/AIDS response of the churches, though in many cases it is a developing response constrained by lack of trained personnel and adequate funds.

Category	Percentage
No response	13
Minimum response	28
Developing response	33
Fully fledged HIV/AIDS programme	26

Source: PACANet, 2003

Amongst the basic needs identified by the churches in order to appropriately address HIV/AIDS in Namibia, stigma and discrimination remains an obstacle (PACANet, 2003).

The 2003 UNAIDS conference in Namibia has heard religious leaders' statements and commitment to fight stigma and discrimination. It believes it is time to lay down its arms in the condom battle with the churches and concentrate more on what they can do to eradicate stigma and discrimination (KIT, 2004). However, there is a dearth of information on stigma and discrimination in churches in Namibia. Hence this study will provide an insight into those discriminatory practices.

1.2 Research problem

After an HIV diagnosis most people seek God to facilitate coping with the ailment, yet some studies suggest that HIV/AIDS remains a stigmatized infection in many churches. Although churches may preach acceptance of people living with HIV/AIDS, there remain an underlying aura of judgment and criticism (PACANet, 2003). According to some religious representatives, coping with HIV/AIDS was different than coping with other terminal diseases that are not sexually transmitted, such as cancer: people living with HIV/AIDS come

to church requesting confession, whereas people fighting cancer want to be healed. After all, the HIV could simply be avoided by adhering to the behavioural conduct outlined by Christian tenets (Genrich & Brathwaite, 2005).

Therefore, the sexual and moral connotation frequently associated with HIV transmission can turn the church into a stigmatizing environment for PLHA. Instead of compassion and comfort, too many of those affected are cast out and neglected by their families, communities, schools and churches. People who become sick suffer in silence, not able to seek medical care or pastoral assistance (UNAIDS, 2003). Thus the focus of this study is to unveil HIV-related stigma and Christ Embassy has been selected as a case study.

There are many problems surrounding HIV stigma and discrimination. Stigmatization may result in loss of respect with the extended family and the community, abuse and repression. In a study conducted by the Malawi Interaction for AIDS Association (2006), the respondents indicated that PLHA were excluded from the usual religious activities due to their HIV status. They reported that they were actually excluded from preaching (70%) and were not allowed to hold influential church positions (30.0%).

Stigma and discrimination make prevention and treatment difficult by forcing the epidemic out of sight and underground. Fear and discriminatory control measures drive HIV/AIDS even further underground, increasing stigma, and making both HIV prevention and support for patients and their families harder to achieve (Jackson, 2002).

Stigma associated with HIV hamper prevention efforts because most people are not willing to test or disclose of serostatus due to the stigma associated with HIV. The association of HIV with promiscuous behaviour deters people from declaring their HIV positive status. “Break the Silence” is a slogan adopted at the International Conference on AIDS and Sexually Transmitted Diseases in Africa in Durban 2000 in response to the reluctance by individuals who are HIV positive to test or disclose their status (Jackson, 2002). The Policy Project (2003) findings show that many PLHA perceive themselves as guilty, a disappointment, and a threat to others. People may forgo treatment rather than face the risk of attracting the stigma attached to those living with the virus; which spreads out to their families, and to those close to them. All these fears make disclosure of HIV-positive status a difficult choice (Masindi, 2004).

1.3 Significance of the study

There is insufficient research that investigates the nature and level of stigma attached to HIV in the church community. To address this gap in literature, the findings of the study will highlight the magnitude of HIV-related stigma and discrimination. People might not be aware that their attitudes and actions are stigmatizing and discriminatory against PLHA. While the extent of stigma and discrimination has not been explicitly documented in Namibia, its impact could be a huge drawback in the fight against HIV/AIDS.

By establishing the underlying causes of stigma, the findings of the study can serve as valuable input to effective intervention, thereby benefitting members of the Christ Embassy Church in Windhoek. This knowledge will help to empower the faith community with skills on how they may interact with HIV-infected people and promote a climate of tolerance and empathy within the church members regardless of their health status. The Policy Project (2003) suggests that before planning a programme to address HIV/AIDS stigma, faith leaders should initiate a faith community wide stigma assessment to gauge the extent of the problem, identify local barriers to stigma mitigation as well as highlight factors enhancing mitigation.

This research is an exploratory study undertaken to unveil the underlying causes of HIV/AIDS related stigma and discrimination perpetuated in the church. Babbie (2005), states that exploratory studies are conducted to satisfy the researcher's curiosity and desire for better understanding, to test the feasibility of undertaking a more extensive study and to develop the methods to be used in any subsequent study. Therefore this study will pave way for wider research, possibly at PhD level which will include both the Christian and the Muslim faith communities in various districts in Namibia.

1.4 Research question

What are the causes of HIV-related stigma and discrimination within the Windhoek Christ Embassy Church?

1.5 Aim

To establish the factors that contributes to HIV-related stigma and discrimination in the Church in order to inform stigma-reduction activities at the Christ Embassy Church.

1.6 Objectives

- To establish the level of HIV/AIDS knowledge of congregants;
- To establish the relationship between knowledge of HIV/AIDS and personal stigma;
- To explore enacted HIV stigma in the Church;
- To establish the causes of HIV-related stigma and discrimination in the Church;
- To make recommendations for effective interventions based on the findings to deal with HIV/AIDS stigma.

1.7 Outline of chapters

Chapter 1 – Introduction. Gives background information and presents the research problem; research question; the objectives and the aim of the study and justification of the study.

Chapter 2 – Literature review. The literature review provides a background of research on HIV-stigma and explores underlying themes and concepts. This chapter starts with defining both stigma and discrimination as they relate to HIV/AIDS and outlines the forms, causes and consequences of HIV-related stigma. Examples of interventions, which have worked to curb this problem at both the community level and in the church, are presented.

Chapter 3 – Research methodology. This chapter indicates the research design or plan of how data will be collected and the methods, procedures and instruments that will be used in the study.

Chapter 4 – Data analysis and discussion of findings. Presents and analyzes the data collected for the research. This chapter will provide an overview and illustration of research findings. It aims to answer the objectives stated in chapter 1.

Chapter 5 – Conclusion and recommendations. This chapter is a closing summary. It also offers strategies for implementing HIV-related stigma reduction activities, which the Church can use.

1.8 Summary

This chapter gave a background to the research topic, the research problem and justifies the importance of the research, presents the goals and objectives. The next chapter will review the literature on HIV/AIDS stigma as a predicament and challenge in the church.

Chapter 2: Literature Review

2.1 Introduction

Literature shows that stigma and discrimination is deep within the faith community (MIAA, 2006). In the era of HIV/AIDS, Faith Based Organizations (FBOs) have been the recipients of many accusations: of being a ‘sleeping giant’; of promoting stigmatizing and discriminating attitudes based on fear and prejudice; of pronouncing harsh moral judgments on those infected; of obstructing the efforts of the secular world in the area of prevention; and of reducing the issues of AIDS to simplistic moral pronouncements (Parry, 2008).

This chapter reviews literature dealing with HIV/AIDS stigma in the faith community. The purpose of the literature review is to collect reliable and valid evidence to understand the underlying factors of HIV-related stigma and discrimination, to document how stigma and discrimination manifest, and to look for ways to reduce stigma and discrimination in FBOs. The literature review consists of the following section: definition of stigma and discrimination, expressions and forms of stigma, causes of HIV stigma, impact of stigma on prevention, faith-based interventions, research gaps and a summary of the literature review.

2.2 Defining stigma and discrimination

For the purpose of this study, the terms ‘stigma’ and ‘discrimination’ are often used together because they practically reinforce each other. According to Morrison (2006), the word ‘stigma’ has Greek origins referring to the marks of physical deformities of foreigners or persons deemed inferior. Christians gave this word a twist by using it to refer to the physical indications of the divine spirit.

Stigma refers to a powerful and discrediting social label that radically changes the way individuals view themselves and are viewed as persons (Canadian HIV/AIDS Legal Network, 1998 in Policy Project, 2003). UNAIDS (2003) defines stigma as the branding or labelling of a person or a group of persons as being unworthy of inclusion in human community, resulting in discrimination and ostracization. Nyblade and MacQuarrie (2006) concur and state, “we do not conceptualize discrimination as separate from stigma, but as the end result of the

process of stigma-in effect, enacted stigma. While stigma refers to the realm of attitudes and perceptions, discrimination relates to action and behaviour.” In other words, discrimination refers to the negative practices that stem from stigma. According to Morrison (2006), discrimination occurs when we give differential or unfair treatment to people based on the negative perceptions. In this study, it refers to unequal treatment based on HIV status or association with someone who is living with HIV/AIDS.

While the above definitions of stigma focuses on the individual, Parker and Aggleton (2003) argue in favour of stigma as a social process which has its origins deep within the structure of society as a whole, and in the norms and values that govern much of everyday life. They regard stigma as a social process in which people out of fear of the disease want to maintain social control by contrasting those who are normal with those who are different. Based on this analysis Ogden and Nyblade (2005), reiterates that stigma and discrimination are used by dominant groups to produce, legitimize, and perpetuate social inequalities, and exert social control through the exclusion of stigmatized groups, limiting the ability of the stigmatized groups or individuals to resist or fight the stigma.

Consciously or not, some people with HIV think that their identity and worth have been damaged or spoiled because they have HIV. This is sometimes called ‘internalized stigma’ (Carter, 2008). It is common that a patient with a stigmatized disease views himself through the lens of that stigma since he shares the same belief systems as the rest of the community (ICRW, 2002). Internal stigma is the shame associated with HIV/AIDS and PLHA’s fear of being discriminated. Some of the commonly observed forms of internalized stigma in patients include loss of hope, feelings of worthlessness and inferiority, and belief in a doomed future. People with internalized stigma also isolate themselves from society, friends and family (Muwanga, 2004). External stigma refers to actual experiences of discrimination – enacted stigma. Enacted HIV-stigma refers to the discrimination and violation of human rights that PLHA or people assumed to be infected with HIV/AIDS may experience. These include domination, oppression, harassment, accusation, exclusion, ridicule or resentment (Morris, 2003; Muwanga, 2004).

In view of the above definitions, it can be deduced that “stigma is harmful, both in itself, since it can lead to feelings of shame, guilt and isolation of people living with HIV/AIDS, and also because negative thoughts often lead individuals to do things that harm others”

(Aggleton & Parker, 2003). The central focus of the current study, however, is placed on the causes, and strategies related to stigma and discrimination in relation to the fight against HIV/AIDS within the faith community.

HIV-related stigma has been further divided into the following categories:

- Instrumental HIV-related stigma – reflection of the fear and apprehension that are likely to be associated with any deadly and transmissible illness (Herek, 1999)
- Symbolic HIV-related stigma – the use of HIV/AIDS to express attitudes toward the social groups of “lifestyles” perceived to be associated with the disease (Herek, 1999)

Research has also distinguished structural stigma from personal stigma. Personal stigma is an individual psychological process that includes prejudicial attitudes and discriminatory behaviours. Whereas structural stigma is formed by sociopolitical forces and represents policies of private and government institutions that reflect the opportunities of the groups that are stigmatized (Corrigan, 1985).

PLHA experience stigma in numerous forms. In a qualitative/quantitative study of four countries (Ethiopia, Tanzania, Vietnam, and Zambia), Ogden and Nyblade (2005) identified four different forms of stigma – physical, social, verbal and institutional as shown in the Table below.

2.3 Forms of Stigma (adapted from Nyblade and Ogden, 2005) *Table 2.2*

Social stigma - Isolated from community • Voyeurism: any interest may be morbid curiosity or mockery rather than genuine concern; • Loss of social role/identity: social “death”, loss of standing and respect	Physical stigma - Isolated, shunned, abandoned • Separate living space, eating utensils • violence
Verbal stigma • Gossip, taunting, scolding; • Labelling: in Africa: “moving skeleton” “walking corpse: and “keys to the mortuary” In Vietnam: “social evils” and “scum of society”	Institutionalized stigma • Barred from jobs, scholarships, visas; • Denial of health services; • Police harassment (e.g. of sex workers, HIV positive activists in China, outreach workers in India)

Verbal stigma: Since the beginning of the epidemic, the powerful metaphors associating HIV with death, guilt and punishment, crime, horror and ‘otherness’ have compounded and legitimated stigmatization. This kind of language derives from, and contributes to, another aspect underpinning blame and distancing: people’s fear of life-threatening illness (UNAIDS, 2005). Some of the names used to refer to PLHA imply that they have no chance of living and are just waiting to die (Kafuko, 2009). An interesting illustration of verbal stigma is the association we have of the word ‘nyambizi’ (submarine) a term used in Tanzania to refer to a person living with HIV. In this usage, the PLHA is stealthy, menacing and deadly. The rest of us, the putatively innocent, are advised to be wary (GAIA, 2005). The print and visual media have reinforced blame by using language that suggests that HIV is a ‘woman’s disease’, a ‘junkie’s disease’, an ‘African disease’, or a ‘gay plague’ (UNAIDS, 2005). There are strong religious undertones to these attitudes and beliefs, which lead to PLHA being labelled as ‘sinners’ or ‘people who misbehave’ (Banteyerga et al, 2003; Chitando, 2007).

Physical stigma: Physical stigma includes isolation such as separate sleeping quarters in the home or a separate seating area in places of worship (ICWR, 2010). Violence is a particularly harsh form of stigma faced principally by women (UNAIDS, 2007). Both women and girls report increased violence at the hands of their partners for requesting condom use, accessing voluntary testing and counselling, refusing sex within or outside marriage or for testing HIV-positive (UNAIDS, 2007).

Social stigma: Social stigma excludes people living with HIV from family and community events, resulting in their loss of power and respect in the community (ICWR, 2010). Isolation includes loss of social networks, decreased visits from neighbours (for fear of contagion), and reduction of daily interactions with family and community and exclusion from family and community events (Ogden & Nyblade, 2005).

Institutionalized stigma: Institutionalized stigma occurs when an institution, such as a school, hospital, church, organizations or employers, practice stigma either actively or passively. People who are already stigmatized often face increased discrimination when diagnosed with HIV, including refusal of services (DFID, undated). HIV infected individuals may face termination of appointment, hostility, denial of gainful employment, forced resignation or retirement (UNAIDS, 2000). Institutionalized stigma has been reinforced,

according to Parker and Aggleton (2002), by religious leaders and organizations, which have used their power to maintain the status quo rather than to challenge negative attitudes towards marginalized groups and PLHA.

2.4 Expressions of stigma and discrimination in the church

In the church community, stigmatization occurs at all levels, from the clergy to the members of the congregation. In the literature, there are glaring examples of the above stated forms of stigma and discrimination of PLHA within the church. According to the DFID/Futures Group (2005), some FBOs have been involved in denouncing or rejecting PLHA – including their own clergy. Negative sanctions have included forcing HIV-positive clergy and members out of parishes, compelling them to confess the ‘sins’ that led to their infection. At a Theological Workshop Focusing on HIV and AIDS-related Stigma, held in Windhoek, 2003, a Roman Catholic priest from the USA, narrated that while visiting many different countries to facilitate HIV/AIDS workshops for pastoral personnel, he has heard the ‘horror stories’ of pastors, refusing to anoint HIV positive people or forcing them to publicly confess their ‘sins’ that caused them to be infected (UNAIDS, 2005). A similar report by Policy Project (2002), states that there are many cases in Africa of PLHA receiving discriminatory treatment, including ostracism, from faith organization because of their status. This has sometimes resulted in PLHA being summoned for special prayers or confessional sessions before congregations, often based on fraudulent and insistent claims about miracle cures for AIDS.

PLHA in the church may face enacted stigma during performance of religious rites. A qualitative study on HIV/AIDS stigma and related discrimination conducted in three sub-Saharan African countries: Ethiopia, Tanzania and Zambia came up with numerous reports of people using separate utensils for drinking holy water, as in this woman’s example,

I went to church to drink holy water. Then a woman snatched the water from me and drank using a different tin [cup] and said, ‘I don’t like to use the same tin for drinking holy water, ‘because she knows that I live with the virus.’ (Banteyerga et al, 2003).

Findings from a qualitative study to examine knowledge of “*HIV stigma and discrimination, attitudes towards people infected and affected by HIV/AIDS, and attitudes and practices among religious leaders, caretakers of children infected with HIV/AIDS in Uganda*” reported

that within the Seventh Day Adventist Church, PLHA would go last during baptism ceremonies. The church has a communal baptismal pool, where they dip those who are receiving the sacrament. It was observed that Christians were uncomfortable about dipping their bodies in a pool, where a PLHA had been. The church adopted a system of requesting the PLHA to go last (Kafuko, 2009).

In some religious denominations, the right of HIV positive people to get married might be infringed upon in cases where mandatory premarital HIV testing has been enforced. Certain Christian groups are unwilling to allow couples to marry unless both have undergone HIV testing. The International Guidelines on HIV/AIDS and Human Rights state that it is clear that the right of people living with HIV is infringed by mandatory premarital testing and/or the requirement of ‘AIDS-free certificates’ as a precondition for the granting of marriage licenses under State laws (Universal Declaration of Human Rights, Article 16). Below are some cases of mandatory premarital HIV testing.

- In 2007, the Anglican Church in Nigeria made it mandatory for native couples wishing to be married by the Church to first take an HIV test. HIV tests are required to help couples make more “informed choices” when choosing marriage partners – Reverend Akintunde Popoola, spokesman for the Anglican Church in Nigeria. (www.christiantoday.com)
- Kabwata Baptist Church in Zambia, conducts about ten weddings on average in a year. *“I do not say they will not get married if they do not take the test. They are free to marry elsewhere.”* – Pastor Mbewe. The seriousness of the requirement is stressed through the church’s wedding application form which has a provision for members to confirm they have taken the test. (www.hopeforafrica.net)
- In Uganda, by 2006, church leaders were requiring an HIV test of couples wishing to marry (Kafuko, 2009).

There have been reports of PLHA being denied decent and dignified burial by the church. Huggins, Baggaley & Nunn (2004) gives an example of a qualitative research carried out by the Women Farmers’ Advancement Network (WOFAN) which examined the nature of stigma and discrimination in rural areas of Kano State, Nigeria in 2003. One of the main findings of the research was that religious leaders played a significant role in promoting

stigma, and one of the main ways in which this manifested itself was in their refusal to perform burial rites on people known or suspected to have died from AIDS-related illnesses. The research also established that it is also common for families to burn the goods and even the houses of people who have died from HIV-related illnesses after their death. This perpetuates fear of PLHA and fear of contracting HIV from casual contact.

2.5 Causes of stigma and discrimination in the church

Literature shows that, there are a host of contextual and theological forces and factors constraining the fight against HIV/AIDS. These are nourishing and perpetrating stigma and discrimination within the faith community (MIAA, 2006). Historical interpretations of leprosy or skin-diseases as the entry of an evil spirit reinforced stigma and discrimination (UNAIDS, 2005). As the Christian faith is prominent in Namibia, it is imperative that the discussion on stigma and discrimination have some context or theology included.

Christian Theology has, sometimes unintentionally, operated in such a ways as to reinforce stigma, and to increase the likelihood of discrimination (UNAIDS, 2005). The reason seems to be that the bible has often been read and interpreted in such a way as to encourage stigmatizing attitudes and practices within the church, and to increase the stigmatization of the vulnerable and marginalized. In many countries both developed and developing – this is due to the perception that HIV/AIDS is a punishment from God yet the stigmatization of the individual is a sin against the Creator God, in whose image all human beings are made (UNAIDS, 2005). Religious doctrines, moral and ethical positions regarding sexual behaviour, sexism and homophobia, and denial of the realities of HIV/AIDS have helped create the perception that those infected have sinned and deserve their “punishment,” increasing the stigma associated with HIV/AIDS (Parker & Aggleton, 2002).

Similar views by the Christian community of regarding HIV/AIDS as a punishment have been expressed in the literature. A baseline assessment conducted in three districts in Malawi reported that close to 40% of religious leaders interviewed felt that HIV was a punishment from God/Allah. Key informants from Mzimba, Ntcheu, Dowa and Mangochi reported that when preaching the clergy referred to those that are positive as receiving punishment for their prostitution (MIAA, 2006). Kopelman (2005); UNAIDS (2005) state that Christians have presented a model of a vindictive God who inflicts HIV/AIDS as a punishment for human

sin. In Uganda, AIDS was thought to be divine punishment for the sin of adultery: Joseph Mayana, a local barrister, said that the Virgin Mary has revealed to him that ‘...no drug will be found for it. The only drug is repentance.’ Groups sprang up there to seek divine absolution, protection or a cure from the Virgin Mary (Watson, 1998 as cited by Kopelman, 2005).

Chitando (2007) points out that the failure to develop a vaccine to cure HIV has been taken by some as confirming God’s punishment of a stubborn and sinful generation. In traditional theology, God rewards good and punishes evil. HIV is attributed to humanity’s refusal to follow God’s commandments. Promiscuity and rebelliousness in all its forms are the reasons why the epidemic exists, according to this line of thinking.

- **Religious versions of the punishment theory**

A punishment theory of disease does not employ causal concept of responsibility but a moral concept of blame or moral responsibility. Kopelman (2005) identifies various forms of this theory, both secular and religious, arguing that all versions are irrational and thwart attempts to fight the pandemic and help those with HIV/AIDS.

According to religious version of the punishment theory of disease, illness is divine punishment; it is inflicted on humans to punish them for an offence, to give them a chance for rehabilitation, to warn them to become more virtuous, to demonstrate that the bad perish or the good will thrive, or to show that some cosmic order requires the punishment of sin (Kopelman, 2005).

According to the secular or non-religious moral versions of the theory of disease, illnesses are the result of punishing effects of irresponsible behaviour, bad habits or weakness of will. Because HIV/AIDS is an infectious disease, it is associated with behaviours such as multiple sex partners, using intravenous drugs and engaging in prostitution (Kopelman, 2005). To elaborate, religious versions hold that disease is divine punishment and secular or moral versions hold that we are punished for blameworthy lifestyles (Kopelman, 2005).

- **The association between sexuality and sin**

The association of sexuality and sin has been singled out as one of the factors that perpetuate stigma and discrimination in the church. UNAIDS (2005), noted that the stigmatization of people living with HIV/AIDS has grown out of the mistaken link, often made in Christian thinking, between sexuality and sin. It includes the widely held assumption that HIV is always contracted as the result of ‘sinful’ sexual relations, and the additional tendency to regard sexual sin as the gravest of all sins. So sex may come to carry the stigma of sinfulness, and is also stigmatized among other sins.

The association of sexuality and sin the Christian tradition is also reiterated by the United Nations Integrated Regional Information Networks (September 21, 2003) which reports that Christian and Muslim leaders attending the 13th International Conference on AIDS and Sexually Transmitted Infections in Africa held in Kenya, spoke of negative attitudes to the virus that were spread by their churches and mosques. At the same conference, an Anglican priest living with HIV, Reverend Jape Heath linked the stigma and discrimination to what he described as his church’s double standards when it came to the concept of ‘sin’. The Anglican Church looked upon those living with HIV as sinners who could be ‘written off’ and that has been the church’s major contribution on the stigma attached to HIV (MIAA, 2006).

In a qualitative study conducted on *“Stigma, Discrimination and Denial in Uganda”* it was clear from interviews undertaken with religious leaders that churches have a somewhat contradictory attitude towards people living with HIV. While stating that “Jesus did not come for the righteous but for sinners,” many Christian leaders clearly regard people with HIV as “promiscuous” wrong-doers. HIV infection frequently implies “promiscuity” or “unfaithfulness”, both sins (GAIA, 2005). One church leader told us that “AIDS” is an epidemic that has come to the world because of promiscuity and this has resulted in AIDS and other STDs (UNAIDS, 2001). HIV became a manifestation of humanity’s sinfulness. The epidemic was interpreted as fulfilling the curses cited in Deuteronomy (28:27), which include God sending incurable diseases to an apostate people. HIV was read as a signifier that the end of the world was drawing near (Luke 21:5-28) (Chitando, 2007).

- **Sin as a failure to take responsibility**

PLHA are held personally responsible for the onset of the disease, for example due to unsafe sexual behaviours (Bos, 2004). Prevention messages suggesting that it is all about “individual’s choice and vigilance” to avoid contracting HIV are also blames for perpetrating stigma and discrimination (DFID/Futures Group, 2005). In a *Review of the HIV and AIDS, Stigma and Faith-based Organizations*, by DFID/Futures Group (2005), it is stated that HIV prevention campaigns emphasize individual choice – for example, promoting abstinence, faithfulness and condom use. Such emphases imply that people who have become HIV positive have been irresponsible through their own actions and omissions as a product of not adopting appropriate HIV prevention behaviours.

- **Silence**

In the literature, there are accusations of the faith community being silent on HIV/AIDS. Some churches are in denial, the problem of HIV/AIDS is not addressed at all. This attitude has seriously weakened the fight against the epidemic. KIT (2004) reports that in the first phase of the pandemic, Christian Church leaders contributed to the suffering of PLHA either by remaining silent or by relating their condition to sin. Gillian Paterson (undated) argues that ending stigma demands that the Church shatters the conspiracy of silence and admits to the presence of AIDS in its midst; and those churches go out of their way to nurture and encourage those who have HIV; because they are the most valuable potential resource they can have in the struggle against AIDS. In a UNAIDS Theological workshop in Windhoek, Reverend Vitillo of the Roman Catholic Church narrates his experience when a pastor of a parish in Scandinavia invited him to speak about AIDS in the church:

“upon my arrival, he seemed very concerned about what I would say. I reassured him that I would never cause scandal in his pulpit. He then admitted that he had never included the word “AIDS” in any of his homilies or public prayers even though this epidemic had already deeply affected numerous people in his country” (UNAIDS, 2005).

Some churches remain silent because they find it difficult to speak the truth. “The truth sometimes exposes the gap between what their leaders and members preach and what they actually do. This creates a huge problem for individuals, for whom the disclosure of stigmatizing information in an unsympathetic, stigmatizing environment can be a fearsome

and risky undertaking” (UNAIDS, 2005). In a study by MIAA (2006), two thirds of the respondents stated that they did not know people living with HIV/AIDS in their congregations. This indicates that disclosure of HIV testing and counselling results is low. According to UNAIDS (2005), stigma feeds on silence and denial. Institutions and communities may fear the stigma that will fall on them if members are found to be carrying a stigmatized condition. Thus the dread of stigmatization becomes more powerful than the demands of truths of the longing for wholeness.

The added tragedy is that when religious communities speak about HIV/AIDS, they often use language that implies shame and judgment, that makes those infected and affected by HIV/AIDS isolate themselves even further. Religious leaders have a reputation for responding to the issue of HIV/AIDS in negative terms. This can be due to their judgmental comments, resistance to condom use, and restricted access to marriages. The religious sector has been largely unwilling to engage in any way that could imply dilution of moral standards. As a result, embracing sex education posed a challenge as any talk on human sexuality has not been welcomed by some religious communities (Xapile, 2009).

The slow response in addressing issues of sexuality has often made it difficult for churches to engage in an honest and realist war on education, care and support of people living with HIV/AIDS (Xapile, 2009). Churches may have condoned a climate of silence and denial at institutional level, diluted or misrepresented the facts in their educational programmes, failed to provide strong, prophetic leadership (UNAIDS, 2005). Other commentators agree that churches have colluded in stigmatizing by their silence in sexual matters. The reason behind this silence, Xapile states that the majority of members in faith-based organizations still lack the knowledge, experience and practical skills needed for intervention. Religious leaders presiding at funeral rites typically do not mention that the deceased died of AIDS-related illnesses, though this is usually out of respect for the fears of the family (GAIA, 2005).

Other factors which have contributed to HIV stigmatization in religious settings are not theologically based, but are instead linked to judgmental misunderstandings about the nature of the epidemic and an accompanying lack of knowledge upon which to act (DFID/Futures Group, 2005).

These include:

- Emphasis on HIV/AIDS as biomedical (rather than social) issues;
- Stereotypical beliefs about who is at risk of HIV infection;
- Lack of knowledge and awareness of the modes of HIV transmission;
- Lack of understanding of underlying factors that contribute to vulnerability to HIV infection;
- Inadequate training of religious leaders in the basics of HIV transmission;
- A lack of specially-developed materials and resources for use in addressing HIV/AIDS in religious settings – for example, interpretations of religious scriptures and readings through an HIV ‘lens’ (DFID/Futures Group, 2005).

In the next section of the literature review, these and other factors leading to HIV-stigma and discrimination across all sectors are reviewed.

2.5.1 Review of cross-cutting factors of stigma and discrimination

Whether or not a disease will become stigmatized depends very much on the nature of the disease. More specifically: 1) whether or not the individual can be blamed or held responsible for its occurrence; 2) whether or not the illness has potentially serious consequences for others; 3) whether or not there are outward manifestations of the illness; and 4) whether or not it results in decreased competence. HIV/AIDS as an illness conform to all the criteria of a stigmatized disease (Fife & Wright, 2000).

In this section, factors perpetuating stigma cutting across different communities are reviewed. A number of factors have been identified from the literature and will each be discussed in this section. In the *Review of HIV/AIDS stigma in Ethiopia, Tanzania, Vietnam and Zambia*, Ogden and Nyblade (2005) explored the root causes of individual perceptions of stigma. They found fundamental similarities in the development and expression of stigmatizing ideas in all contexts. These included fear of contagion through everyday contact, a preoccupation with unlikely modes of transmission, and an association of the disease with immorality.

HIV/AIDS is a life-threatening illness that people are afraid of contracting (Parker & Aggleton, 2002). Several studies have established that the basis of HIV/AIDS-related stigma

in Africa is fear of contagion through casual contact, and thus it is powered by inaccurate understandings of HIV transmission. Casual contact fears are deeply rooted, even among people who presumably know better. It is possible that the more patently ill a person is, the more likely she or he will be stigmatized (GAIA, 2005). People with apparent signs of AIDS such as Kaposi's sarcoma and weight and hair loss are unfortunately more likely to experience this kind of rejection (Latino, 2006).

Lack of knowledge results in fear that HIV could be transmitted through ordinary, daily interactions with people living with HIV/AIDS such as kissing, shaking hands, sleeping in the same room and eating together with an infected person (Ogden & Nyblade, 2005). They established that many respondents do not understand that there is a difference between HIV and AIDS, how the disease progresses, and what the longevity of a person with HIV is. In their study, less than one-third of the respondents in Ethiopia knew the difference between HIV and AIDS. Many respondents in all the three countries included in the study believed that a person with HIV will die very quickly, if not immediately person (Ogden & Nyblade, 2005).

The perceived 'untreatability' of AIDS is a key factor contributing to stigmatization (UNAIDS, 2002). With HIV/AIDS we are dealing with a disease that is both infectious and lethal, or, if not lethal, so serious that it requires drastic changes in life style (particularly as far as one's sex life is concerned), as well as continued treatment with drugs that are not only costly but that have adverse and quite discomforting side-effects (van Niekerk, undated). Based on this thought, people often suspect that individuals with HIV or AIDS pose a threat to the community at large; hence they are discriminated against (GAIA, 2005).

Because of people's deep fear of AIDS, they often hold irrational fears about HIV risk that they do not hold with regard to other Sexually Transmitted Infection (STIs). Despite the introduction of Antiretroviral Therapy (ART), HIV remains a chronic and incurable condition surrounded by fear and myths (Jackson, 2002). Many believe in those myths even within the church (Genrich & Brathwaite, 2005). Chitando (2007) points out that those misconceptions about the epidemic are common among pastors. He gives an example of one pastor at a preachers' workshop in Tsholotsho, rural Zimbabwe in 2006, who described HIV/AIDS as "that disease one gets from South Africa." The pastor was convinced that AIDS was not a Zimbabwean reality. Spercher (2007) attributes ignorance to the fact that "because we don't

talk about HIV/AIDS, we perpetuate myths about the disease, how people get it, who it affects, how it can be treated.”

2.6 Implications for HIV prevention

The belief that HIV is a punishment from God has implications for prevention. As stated in Banteyerga et al (2003), it enhances a sense of fatalism about individual ability to protect oneself from HIV, ‘if it is the will of God’, therefore there is really nothing that can be done to protect oneself. It also leads to the belief that if God gives HIV, He also has the power to take away HIV. If a person living with HIV asks God’s forgiveness, is truly repentant for their sins, and believes enough in God’s healing powers, then God will remove HIV from the person. In the same study, it is noted that parents with deeper religious beliefs console their PLHA family members mentioning God as the ultimate power to cure patients, and the holy water is believed to be God’s way of treating patients (Banteyerga, et al, 2003).

HIV-related stigma in the church can negatively affect preventive behaviours such as condom use. Findings from a qualitative study conducted in Uganda, reveal that the Anglican Church advocates for behaviour change and condemns the advertisement of condom use as an HIV prevention mechanism. The church accepts condom use in marriage under two circumstances: a) for family planning; b) for prevention of HIV infection and STIs among discordant couples. In the same study, it is noted that the Pentecostal Church is also against the generic promotion of condom used as an HIV prevention mechanism. Interviews also revealed only two circumstances in which exceptions of condoms are acceptable, namely: as a birth control mechanism between married persons and between discordant couples (Kafuko, 2009). The Catholic Church’s view is that condom use ignores the real cause of the problem and encourages permissiveness, corroding the moral fibre of society (Catholic Bishops of Uganda, 1989).

HIV-related stigma also undermine prevention by making people afraid to find out whether or not they are infected, for fear of the reactions of others. In Botswana, a survey of HIV patients receiving antiretroviral therapy (ART) found that 40 percent had delayed getting tested for HIV mostly due to stigma (Wolfe et al, 2006).

Prevention programmes are undermined when people do not want to be associated with the disease. According to Brooks RA, et al. (2005) stigma surrounding HIV, homosexuality, commercial sex work and drug use make it difficult for HIV prevention services to be offered in a variety of settings. While it is widely accepted that HIV prevention should be integrated into a broader health and community context, many community venues such as churches, businesses, jails, prisons and schools have resisted incorporating frank discussions of HIV.

2.7 Addressing stigma and discrimination in the church

From the previous section it is evident that stigma has an impact on prevention and treatment, therefore it is important to address it directly. “Whilst some analysts suggest that HIV-related stigma and discrimination are pervasive within FBOs, there is also a body of documented HIV/AIDS-response activities that take place within and via FBOs that are currently growing rapidly” (DFID/Futures Group, 2005). This section will look at ways of responding to the problem in the context of FBOs. Most of the responses are adopted from a guide by the Siyam’kela Project (2003) entitled *‘Tacking HIV/AIDS: Guidelines for Faith Based Organizations.’* The guidelines provide faith leaders, HIV/AIDS committees, PLHA in the faith community and opinion leaders within the faith-based sector with practical and user-friendly recommendations on how to create an environment free of HIV/AIDS stigma (Siyam’kela, 2003).

Breaking the silence: It is believed that churches cannot address HIV/AIDS without first breaking the silence that surrounds issues of sex, drug addiction, sin and death (Paterson, undated). In an HIV/AIDS-supportive environment, disclosure is encouraged as it breaks the silence. It also allows a PLHA to tap into existing support services (Policy Project, 2003). PLHA should be given room to speak for themselves because they are essential allies, if they can be open about their own infection they can set as role models for HIV prevention and support: they give a face and a voice to the epidemic, making it real for those in denial (Jackson, 2002).

Training: As previously stated, religious leaders lack training in the basics of HIV transmission (DFID/Futures Group, 2005). Religious leaders should regularly avail themselves of accurate and timely information on HIV/AIDS and disseminate this aggressively (GAIA, 2005). The Catholic AIDS Action in Namibia trains pastors, not only

by informing them, but by encouraging participatory training. Often they are unaware of how much they use discriminatory language, and therefore increase stigma, nor of how important their role is in the fight against the pandemic (KIT, 2004).

Mainstream HIV/AIDS stigma and guideline policies: HIV/AIDS and stigma-mitigation standards should be mainstreamed. A destigmatizing approach to incorporating HIV/AIDS in all pastoral services, for example, funerals, pre-marital counselling, confirmation or baptism should be spelt out in policy development. This will ensure that stigma-mitigation is taken seriously and addressed in various aspects of faith (Policy Project, 2003).

Include PLHAs in positions of leadership: It is recommended that FBOs consider appointing faith leaders openly living with HIV/AIDS. These leaders could be positive role models and advocates for a stigma-free environment (Policy Project, 2003).

Involve PLHA to a greater extent: The principle of the Greater Involvement of People Living with HIV/AIDS commonly referred to as the GIPA principle should be applied to FBOs. The GIPA principle encourages organizations to involve PLHA in addressing the pandemic and to act as HIV/AIDS advocates for positive living. PLHA have unique experiences and expertise that should be used as a resource (Policy Project, 2003).

Raise awareness: Faith communities should be sensitized to HIV/AIDS stigma, how it functions and consequences to PLHA, the faith group and society. This could be done by adding to existing HIV/AIDS awareness-raising activities (GAIA, 2005).

Voluntary Counselling and Testing (VCT): Religious leaders should be persuasive concerning VCT and should be tested with widespread publicity that they have done so (GAIA, 2005). PLHA are receptive to faith-based counseling and support provided by religious leaders and congregation members (Genrich & Brathwaite, 2005).

2.8 Gap in our knowledge about HIV stigma and discrimination in faith communities

There is a dearth of information on the existence of HIV/AIDS-related stigma and discrimination in Namibia. The lack of research specifically on HIV-related stigma and discrimination in churches is a motivating factor to explore this problem at the Windhoek Christ Embassy Church. “Information about knowledge on HIV/AIDS and attitudes towards PLHA in the churches is lacking, possibly because generally the church is not regarded as a high-risk site in HIV transmission” (Genrich & Brathwaite, 2005). Previous studies do not disclose much about practices related to stigma and discrimination in the church either due to the fact that not much research has been done yet or religious leaders and faith communities do not openly disclose practices amongst themselves that promote stigma and discrimination (Huggins, Baggaley & Nunn, 2004).

At the Theological Workshop held in Windhoek, local Namibians were able to recount their own experiences of stigma and discrimination. Only their names were listed, yet none of their experiences were documented in the workshop report.

2.9 Summary

The review of literature has shown that coping with HIV/AIDS is more complicated when compared to other chronic illnesses, because of the stigma and discrimination associated with it. Some of the most often quoted words to reinforce this statement are the words of Gideon Byamugisha, an Anglican priest from Uganda, who himself is HIV positive:

It is now common knowledge that in HIV/AIDS, it is not the condition itself that hurts most (because many other diseases and conditions lead to serious suffering and death), but the stigma and the possibility of rejection and discrimination, misunderstanding and loss of trust that HIV positive people have to deal with (van Wyngaard, 2005).

Testing HIV positive is likely to be a traumatic experience and some people turn to the church for spiritual support, yet some churches have responded negatively to the issues of HIV/AIDS. Such attitudes and practices have been exacerbated by a number of factors some of which have been reviewed in this chapter.

Chapter 3: Methodology

3.1 Introduction

The chapter describes the methodology that was used in the course of collecting data. It presents the methods, ethical considerations, procedures and instruments used in the study.

3.2 Paradigm

The research used the quantitative research approach. The advantage of quantitative research is that it is objective, easy to replicate and so has a high reliability; and results can be reduced to a few numerical statistics and be measured so that comparisons can be made (Sarantakos, 2002).

3.3 Research design

Research design refers to the outline, plan, or strategy specifying the procedure to be used on seeking an answer to the research question. It specifies such things as how to collect and analyze the data (Christensen, 2007). In this study, a small-scale survey of 60 respondents was used to assess the causes of HIV stigma in the church for the purposes of the mini-thesis. Christensen (2007) defines a survey as a method of collecting standardized information by interviewing a representative sample of some population. The survey method is a technique that is applicable to a wide range of problems and helps us to understand why a particular phenomenon occurred.

3.4 Target population

The surveys were distributed to a convenience sample of eligible >21 years old parishioners of the Christ Embassy Church in Windhoek who belonged to a cell group, and sufficiently fluent in English to complete the survey instrument. Cell groups meet at least once a week at different venues convenient to them. Not all church members belong to a cell group – membership is voluntary.

3.5 Sampling method

Sampling means deliberately limiting the number of cases in the study. Usually a population is too large, making it impossible and unnecessary to include all cases. The congregation of the Christ Embassy was too large to include every member in the study. The study used a non-probability sampling method, which does not give all cases in the population equal chances to fall into the sample. “Convenience sampling is a non-probability sampling technique whereby the sample of participants selected is based on convenience and includes individuals who are readily available, for example, people at a meeting may be specified as the sample” (Christensen, 2007). It only includes participants who are willing to take part. Cell group members are readily available to the researcher at their week-end or mid-week prayer meetings. They were easily reached without spending a great deal of time and money.

Not all cell groups were included in the study. Snowball sampling was used to pick the cell groups. One cell group leader was asked to provide the names and contact details of other cell leaders whom the researcher could contact. This was repeated until the researcher obtained the sufficient number of respondents.

3.6 Measuring instrument

To collect quantitative data using the survey method, a questionnaire was administered. “A questionnaire is a vital tool for quantitative research. It is a set of questions used to elicit research, answers to the problems, or research issues of the study” (UNESCO, undated). According to Saratankos (2002), questionnaires are cost-effective; produce quick results; offer a great assurance to anonymity and less opportunity for bias; and can be completed at the respondents’ convenience.

The questionnaire was designed by the researcher and most of the questionnaire items were adopted from Nyblade and MacQuarrie (2006) “*Can We Measure HIV/AIDS-related Stigma and Discrimination.*” Questions from section G were adopted from the operational research by the Malawi Interfaith AIDS Association (2006). The questionnaire consisted of closed questions where all possible answers were provided, and respondents were required to tick the appropriate box for the answer given.

The questionnaire was in English and consisted of seven sections;

Section A: Socio-demographic data of the respondents

Section B: Knowledge about HIV and AIDS

Section C: Fear of casual transmission and refusal of contact with people living with HIV and AIDS;

Section D: Values (shame, blame and judgment);

Section E: Enacted stigma (these indicators reflect the extent of discrimination of PLHA);

Section F: Disclosure;

Section G: Sources of HIV/AIDS information

3.7 Data collection

The researcher attended cell group meetings during the data collection process. An appointment schedule was drawn up with the cell leaders. The data collection process included the following procedures. The researcher presented the letter of approval from the Pastor to the cell group leader. The researcher introduced the study and explained that its main objective was to establish the underlying causes of HIV-related stigma in the church. The researcher also explained that the results would contribute to a mini-thesis to be submitted in partial fulfillment of the Master of Philosophy degree in HIV/AIDS Management at the University of Stellenbosch.

Consent forms and questionnaires were distributed and respondents were asked to do the following:

- Read the consent form and ask for any ambiguities;
- Sign the consent form;
- Read the questionnaire and ask for clarification to any questions to the researcher that may seem unclear;
- Complete the questionnaire individually on-site, during the cell group meeting;
- Return the completed questionnaire to the researcher.

The questionnaires were completed individually on-site in approximately 30 minutes and returned to the researcher. This was done to clear up any ambiguities, to ensure a high response rate and to avoid contamination of answers caused by discussing the questions with

friends/family. Not all members of the selected cell groups participated, but there was a 100 percent return rate of the questionnaires. Sixty (60) questionnaires were given out and all were returned because they were filled on-site. Respondents had a right to answer questions they did not want to answer and still remain in the study.

3.8 Data analysis

The collected data was cleared and entered into Microsoft Office Excel 2007 for analysis. Data analysis involves examining, sorting, categorizing, evaluating, comparing, synthesizing and contemplating the coded data, as well as reviewing the raw and recorded data (UNESCO, undated). Before data entry, each questionnaire was coded and cleared. In this study, data analysis was mainly descriptive in nature, outlining the proportion of answers to question items. Descriptive statistical methods provide a means to classify and summarize the numerical data obtained through questionnaires. Charts, graphs, frequency distribution tables, provided a graphic representation of data and turned it into valuable information.

3.9 Ethical procedures

A number of measures have been taken to observe basic ethical standards.

3.9.1 Institutional approval

Prior to the submission of the research proposal, the researcher sought approval from the church pastor to conduct the study. The letter of approval, and other necessary documentation was submitted to the University of Stellenbosch Ethics Committee, who gave its approval prior to commencement of the research.

3.9.2 Informed consent

The principles of informed consent refers to the fact that a person, once given the pertinent information, is competent and legally free to make a decision as to whether to participate in a given research study (Christensen, 2007). In carrying out the survey, the informed consent process outlined the following: a) purpose of the study; b) procedures; c) potential risks and discomforts; d) potential benefits to subjects and to society; e) payment for participation; f)

confidentiality; g) participation and withdrawal h) identification of investigators i) rights of research participation. The researcher highlighted that participation was on a voluntary basis and respondents had a right to withdraw at any given time without facing any consequences.

3.9.3 Confidentiality, anonymity and privacy

The names of the participants who filled in the consent forms were not disclosed in the study findings nor linked to the completed questionnaires. The questionnaires were completed anonymously (no names attached) to ensure confidentiality and to protect the privacy of the respondents. Information obtained from the survey was treated as confidential. All electronic files were password protected. Hard copies of the completed consent forms and questionnaires were filed in a secure cabinet.

Summary

This chapter is a description of the research methodology. It also outlines the data collection method, population investigated for the purposes of this study, the instrument used to collect data, ethical considerations and sampling technique. The next chapter will focus on data analysis and discussion of findings.

Chapter 4: Data analysis and discussion of findings

4.1 Introduction

In this chapter, the data that emanated from the questionnaires of the survey conducted with 60 respondents is interpreted with the use of frequency tables, pie charts, bar graphs and histograms. The discussion is presented under the 5 objectives of this study.

4.2 Socio-demographic data (N=60)

Demographic data of the 60 respondents was categorized according to age, gender, marital status and the level of education.

Age of the respondents

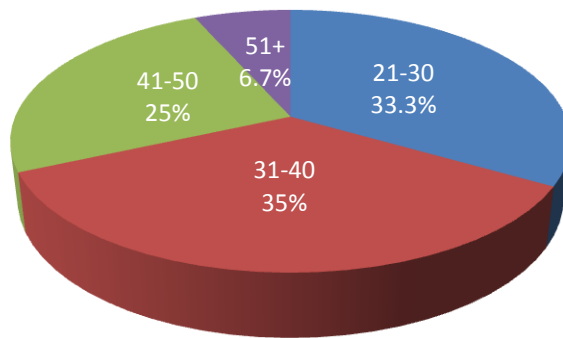


Figure 1: Age

35 percent of respondents fell within the 31-40 age range. 33.3 percent were in the 21-30 age range. 6.7 percent were 51 years and above. 25 percent were 41-50 years. The study does not measure the responses of the participants in relation to their respective age groups.

Gender

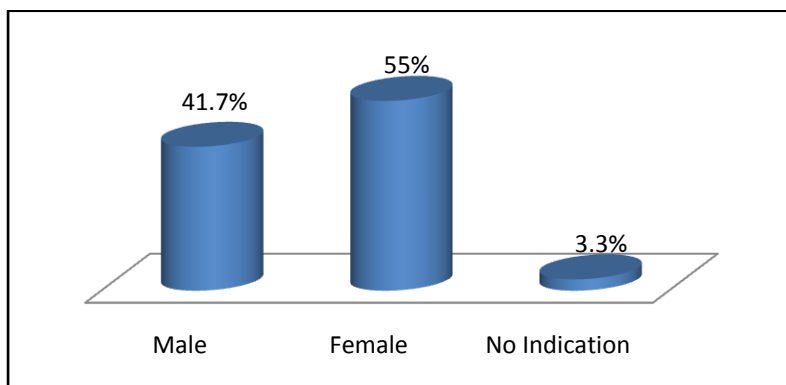


Figure 2: Gender

The gender grouping of the respondents is represented above. Two people (3.3%) did not indicate their gender. Female congregants were in the majority at 55 percent, while male respondents formed 41.7 percent of the survey. The study does not measure the responses of the participants in relation to their respective gender.

Marital Status

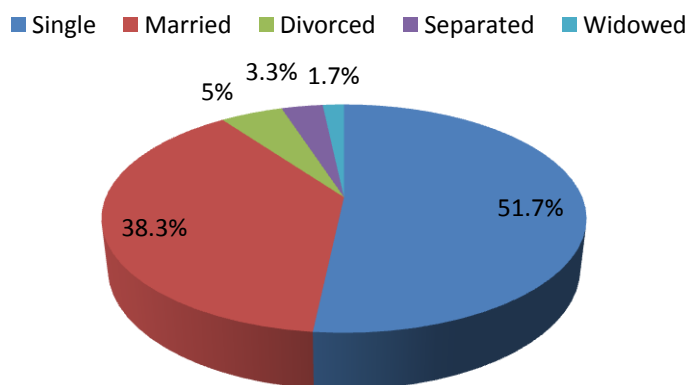


Figure 3: Marital Status

51.7 percent indicated that they were single, 38.3 percent were married. 5 percent were divorced, 3.3 percent were separated. Only 1.7 percent was widowed. The study does not measure the responses of the participants in relation to their respective marital status.

Level of Education

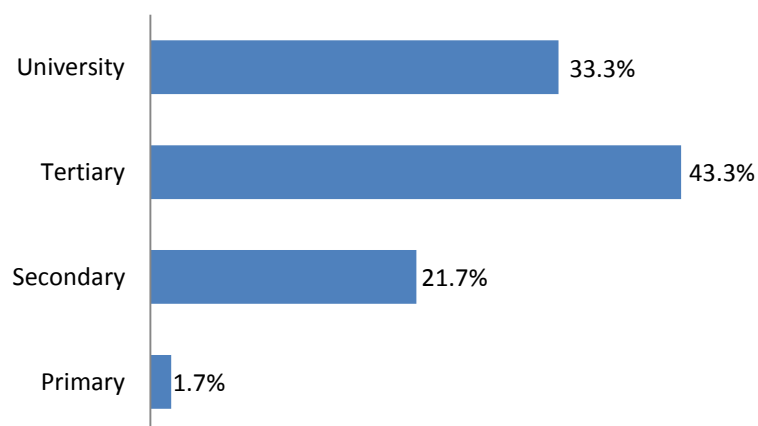


Figure 4: Education

33.3 percent of the respondents have attained university education, 43.3 percent have tertiary education. 21.7 have secondary education (grade 8-12), while 1.7 percent attended primary level education (grade 1-7).

4.3 Knowledge of HIV and AIDS (N=60)

	Frequency of responses			
Questions	True	False	DK	Correct
	No. (%)	No. (%)	No. (%)	
There is no difference between HIV and AIDS	15 (25%)	41 (68.3%)	4 (6.7%)	68.3
A person can have HIV without becoming ill with AIDS	46 (76.7%)	12 (20%)	2 (3.3%)	76.7
People who look healthy are not infected with HIV	8 (13.3%)	52 (86.7)	0 (0%)	86.7
Sexual contact is the primary means of HIV transmission	55 (91.7%)	3 (5%)	2 (3.3%)	91.7
A person can get HIV by being bitten by a mosquito or any insect	5 (8.3%)	54 (90%)	1 (1.7%)	90
HIV can be transmitted from mother to child through breast-feeding	45 (75%)	12 (20%)	3 (5%)	75
AIDS can be spread through the use of contaminated needles/blades	57 (95%)	1 (1.7%)	2 (3.3%)	95
A pregnant woman infected with HIV can decrease the chance of transmitting the virus to the unborn child by taking ARVs	49 (81.7%)	6 (10%)	5 (8.3%)	81.7
People can reduce their chances of getting HIV by having a monogamous sexual relationship with an HIV-negative partner	37 (61.7%)	13 (21.7%)	10 (16.7%)	61.7
Antiretroviral treatment reduces the amount of HIV in the person's body	39 (65%)	14 (23.3%)	7 (11.7%)	65
An HIV test can remain negative for a few months after someone is infected	46 (76.7%)	11 (18.3%)	3 (5%)	76.7

Questions to test knowledge of HIV and AIDS required a True, False or Don't know response. Knowledge on how HIV infection is transmitted is high with 91.7 percent acknowledging that sexual contact is the primary means of HIV transmission. 90 percent indicated that a person cannot get infected by being bitten by mosquitoes. 75 percent indicated that HIV can be transmitted from mother to child through breast-feeding, while 20 percent considered the statement as false. 95 percent are aware that AIDS can be spread through the use of contaminated needles/blades and 81.7 percent knew that a pregnant woman infected with HIV can decrease the chance of transmitting the virus to the unborn child by taking ARVs. 65 percent knew that antiretroviral treatment reduces the amount of HIV in the person's body, while 11.7 percent were not aware. 23.3 percent considered this statement as false. 61.7 percent of the congregants indicated that people can reduce their chances of getting HIV if they stick to one partner who is HIV-negative. 21.7 percent did not agree with the statement while 16.7 percent did not know.

76.7 percent recognized that an HIV test can remain negative for a few months after someone is infected, while 18.3 percent did not agree. In spite of the high level of knowledge on HIV transmission, 25 percent indicated that there is no difference between HIV and AIDS. While 20 percent considered as false the statement that a person can have HIV without becoming ill with AIDS, 76.7 percent agreed. 86.7 percent indicated as false the statement that people who look healthy are not infected with HIV, but 13.3 percent said that it was true.

Level of HIV Knowledge Scale: frequency distribution of scale scores

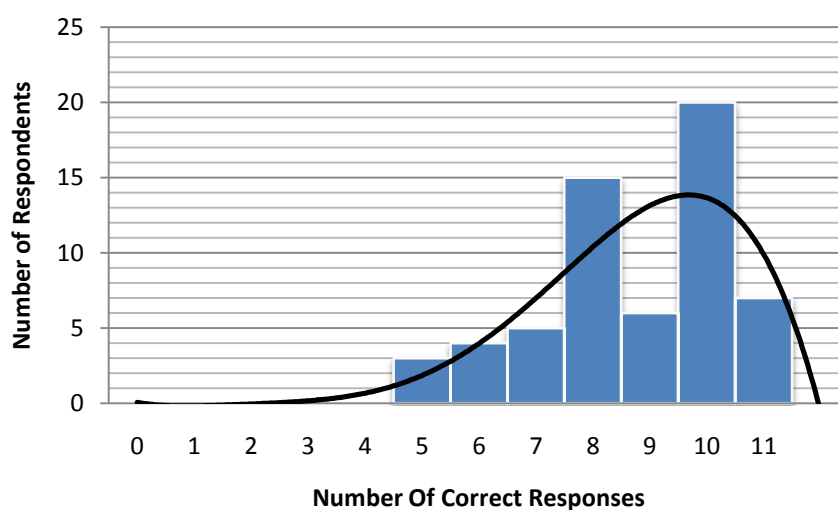


Figure 5

The histogram above is a representation of the performance of respondents on HIV knowledge. From the histogram, it can be interpreted that 3 respondents answered 5 questions correctly out of the 11 questions on knowledge. 20 respondents answered 10 questions correctly. 7 respondents answered all the 11 questions correctly. The trend line represents the trend of knowledge and it follows a normal distribution with parameters, mean = 8.684 and standard deviation = 1.225731. The trend line is skewed to the left; this means that no respondents scored less than 5 correct responses.

Mean (8.684) indicates that the respondent with average knowledge scored about 9 out of 11 questions correctly. A standard deviation (1.225731) means that the respondent with average knowledge scored between 8 and 10 questions correctly. This implies high levels of knowledge of HIV/AIDS.

4.4 Personal Stigma indicators (N = 60)

Fears of Casual Contact	Stigma (Yes)	No Stigma (No)
Do you have fears of being infected If you share the same utensils with someone who is HIV positive?	26 (43.3%)	34 (56.7%)
If you drink from the same communion cup with an HIV-infected person?	18 (30%)	42 (70%)
If you shake hands with someone who is HIV positive?	0 (0%)	60 (100%)
If you sit next to someone who is showing signs of AIDS?	0 (0%)	60 (100%)
If you use the same toilet with someone who is HIV positive?	13 (21.7%)	47 (78.3%)
If you are baptized in the same water with PLHA	11 (18.3%)	49 (81.7%)
If you touch a PLHA	2 (3.3%)	58 (96.7%)
If you are exposed to the sweat of a PLHA	29 (48.3%)	31 (51.7%)

Is it safe for a Sunday school teacher who is HIV positive to work with children?	60 (no Stigma) (100%)	0 (stigma) (0%)
Values (shame, blame, judgment)	Stigma (Agree)	No Stigma (Disagree)
HIV is a punishment from God	37 (61.7%)	23 (38.3%)
PLHA have not followed the Word of God	35 (58.3%)	25 (41.7%)
PLHA are cursed	27 (45%)	33 (55%)
People with HIV are promiscuous	17 (28.3%)	43 (71.7%)
PLHA lose respect in the congregation	6 (10%)	54 (90%)
PLHA do not deserve any support	1 (1.7%)	59 (98.3%)
People with HIV should feel ashamed of themselves	19 (31.7%)	41 (68.3%)
I would feel ashamed if I was HIV positive	23 (38.3%)	37 (61.7%)
People with HIV have themselves to blame	26 (43.3%)	34 (56.7%)
If you have a family member with HIV, would you feel ashamed?	17 (28.3%)	43 (71.7%)
Disclosure	Stigma	No Stigma
If a family member has HIV, would you keep it a secret?	23 (38.3%)	37 (61.7%)
If you test positive, would you share your results with anyone?	27 (45%)	33 (55%)

The responses to personal stigma are represented in the Table above. Questions to ascertain if respondents' perceptions of fears of being infected through casual contact required a Yes or No response. 56.7 percent are not afraid of contracting HIV if they share the same utensils with someone who is HIV positive while 43.3 percent do have fear of using the same utensils.

70 percent would drink from the same communion cup with an HIV-infected person, but 30 percent would not. There was a 100 percent response rate to indicate no fear of transmission by shaking of hands with PLHA and also by sitting next to someone showing symptoms of AIDS. 78.3 percent do not fear to use the same toilet and 81.7 would be baptized in the same water because they do not fear contracting HIV. 18.3 percent thought that being baptized in the same water would risk transmission. 96.7 percent felt that they will not contract the virus by touching an infected person. 51.7 percent do not fear transmission through exposure to sweat, but 48.3 percent have fears. 100 percent felt that it is safe for a Sunday school teacher who is HIV positive to work with children.

The section on values looks at how the respondents perceive those people living with HIV in the congregation. This domain encompasses items on judgment, shame and blame for the responsibility for HIV infection on the HIV-positive individual. It also entails labelling, and devaluing of PLHA. The majority of respondents, (61.7%) indicated that HIV is a punishment from God. 58.3 percent believed that PLHA have not followed the word of God. 45 percent regard PLHA as cursed. 28.3 percent associate PLHA with promiscuity. On the contrary, 98.3 percent disagreed with the statement that PLHA do not deserve any support. 90 percent also disagreed that PLHA lose respect in the congregation. 68 percent indicated that PLHA should feel ashamed of themselves and 61.7 percent would feel ashamed if they contract HIV. But 71.7 percent would not feel ashamed if they have a family member who is HIV positive. 43.3 percent apportion blame on PLHA for contracting the virus.

On disclosure respondents provided a Yes or No answer to the question whether they would keep it a secret if a family member has HIV. 61.7 percent would not keep it a secret, while 38.3 percent would not reveal. 55 percent would share the test results if they test positive. 45 percent would not disclose their results to anyone.

4.4.1 Correlations between Knowledge and Personal stigma (fears of casual contact, values, disclosure)

Pearson correlation coefficient was used to measure the degree of relationship for four variables namely knowledge, fears of casual contact, values and disclosure. Correlation is used to seek if the presumed relationship between the variables actually exists. A correlation coefficient can either be positive or negative.

- **The relationship between knowledge and fears of casual contact is rated to be:**

$r = -0.196990621$ according to Pearson's correlation. This implies a weak negative relationship. A negative relationship indicates that as the values of one variable increase, the values of the other variable decrease. In this case, as knowledge increases, the fear of casual contact decreases. The coefficient (-0.196990621) is very close to zero, but it is not zero. This means that there is a relationship between knowledge and fears casual contact, but the relationship is very weak. If a relationship is between 0 and 0.5, it is said to be a weak relationship, which means knowledge is a factor in decreasing fears of casual contact, but there are other factors that contribute to decreasing fears of transmission through casual contact. Scoring was done by allocating one point for every response that agreed with a statement that indicated stigma. A score of 1 indicated stigma. A higher score indicated higher levels of stigma (fears of casual contact) of the respondents. The number of positive answers (participants replied 'yes') with the exception of the last question (where a 'no' indicated stigma), was calculated for a total score of fears of casual contact. The maximum score that could be attained was a nine.

- **The relationship between knowledge and values (shame, blame, judgment) is rated to be:**

$r = -0.201551237$ according to Pearson's correlation. This implies a weak negative relationship. As knowledge increases, the values associated with stigma decrease. The coefficient (-0.201551237) is very close to zero, but it is not zero. This means that there is a relationship between knowledge and values, but the relationship is very weak. This implies that there are other factors that contribute to less stigmatizing values other than knowledge. Scoring was done by allocating one point for every response that agreed with a statement that indicated stigma. The number of positive answers (participants replied 'agree') indicated the levels of stigmatizing values. A higher score indicated more stigma levels of the respondents. The maximum score that could be attained was 10.

- **The relationship between knowledge and disclosure is rated to be:**

$r = -0.085346504$ according to Pearson's correlation. This implies a weak negative relationship. As knowledge increases, the unwillingness to disclose decrease. The coefficient (-0.201551237) is very close to zero, but it is not zero. This means that there is a relationship between knowledge and disclosure, but the relationship is very weak. This

implies that there are other factors that contribute to willingness to disclose other than knowledge. Scoring was done by allocating one point for every response that agreed with a statement that indicated stigma. The total achievable score was 2. In this section we had only two questions out of six that denoted personal stigma.

Representation of the Correlations

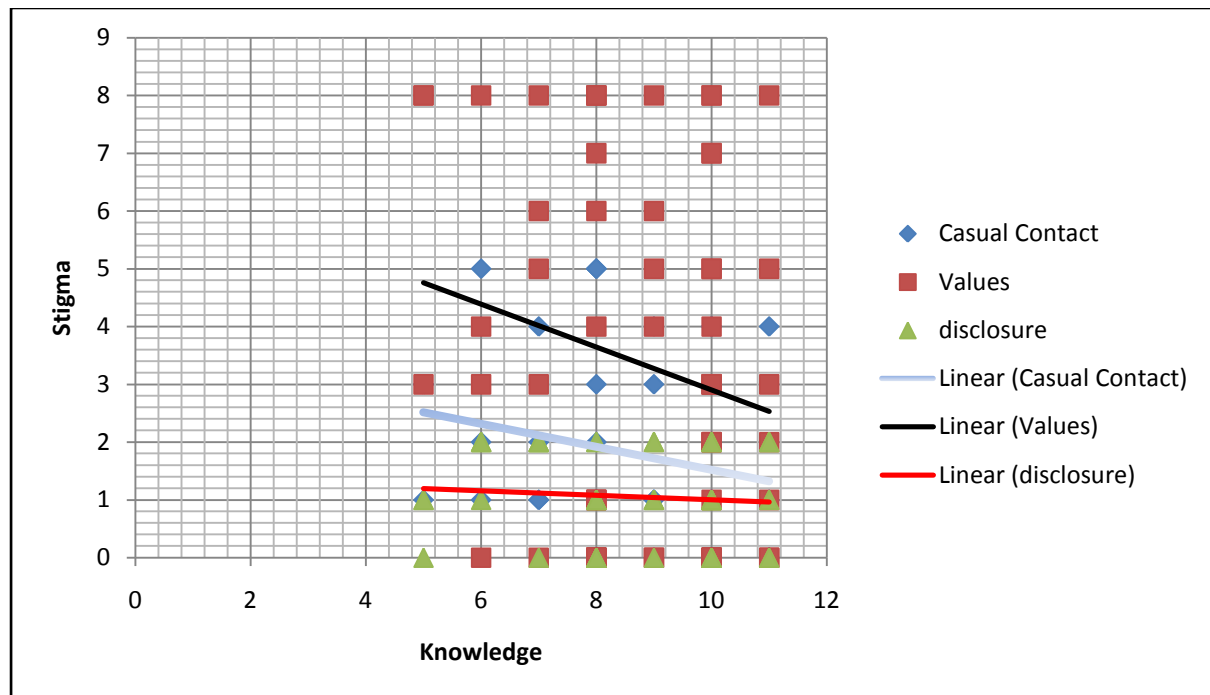


Figure 6

The scatter plot above shows the trends based on the correlations of knowledge against the fears of casual contact, values and disclosure. The three trend lines show the same pattern of decrease in stigma with increasing knowledge.

According to the scatter plot, the values that respondents have are less likely to be influenced by the level of knowledge as compared to the fears of casual contact and willingness to disclose. Thus the values are highly placed on the scatter plot. Disclosure is lowly placed indicating that it is more likely to be influenced by the increase in knowledge.

4.5 Enacted Stigma (n=60)

Respondents were asked to report on the practices that they perceive PLHA were forced to deal with in the church. 11.7 percent indicated verbal abuse through gossip, 13.3 percent were not sure. None of the respondents knew of anyone that has been teased because of HIV status. When the respondents were asked if they knew of anyone who has been excluded from participating fully in some church activities because they were HIV positive, 81.7 percent were not aware, only 3.3 percent indicated that such exclusions take place. 5 percent gave a positive response to isolation, while 10 percent were not aware of anyone

who had been isolated. 11.7 percent knew of someone who had lost friends, while 10 percent were not sure. Generally enacted stigma was relatively low in this sample. The responses on the existence of enacted stigma were in the negative as indicated in Box 4.5 above.

Do you know someone in the church who has had the following happen to him/her because of HIV or AIDS?

<u>Negative responses</u>	<u>No.</u>	<u>%</u>
Gossiped about	45	(75%)
Teased or sworn at	48	(80%)
Lost respect/standing within the church	50	(83.3%)
No longer visited, or visited less frequently by members		
Of the church	43	(71.7%)
Excluded from participating fully		
In church activities	49	81.7%)
Isolated within the church	51	(85%)
Lost friends within the church	47	(78.3%)
Required to take HIV testing in order to marry in the church	37	(61.7%)
<i>(Box 4.5)</i>		

4.6 Disclosure (n=60)

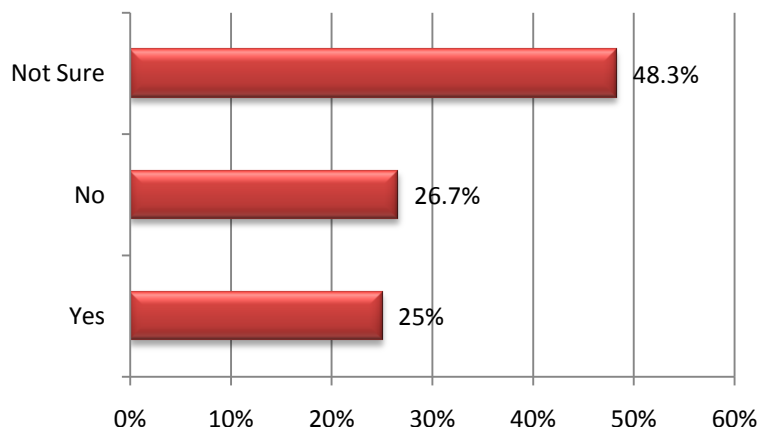


Figure 7

The question required respondents to indicate whether they knew of people who were living openly with HIV/AIDS in the church. 48.3 percent were not sure and 26.7 percent did not know of PLHA. Only 25 percent stated that they knew of such persons in the congregation.

Forum for Disclosure

Are people in your congregation given a forum to disclose their HIV status?

Yes	10	16.7%
No	30	50%
Not Sure	20	33.3%

Box 4.6

Respondents were asked if there was a forum to disclose HIV status in church. 50 percent responded in the negative. 33.3 percent were not sure of the existence of such a forum, and only 16.7 percent agreed with the statement.

Primary way to know HIV status of other church members

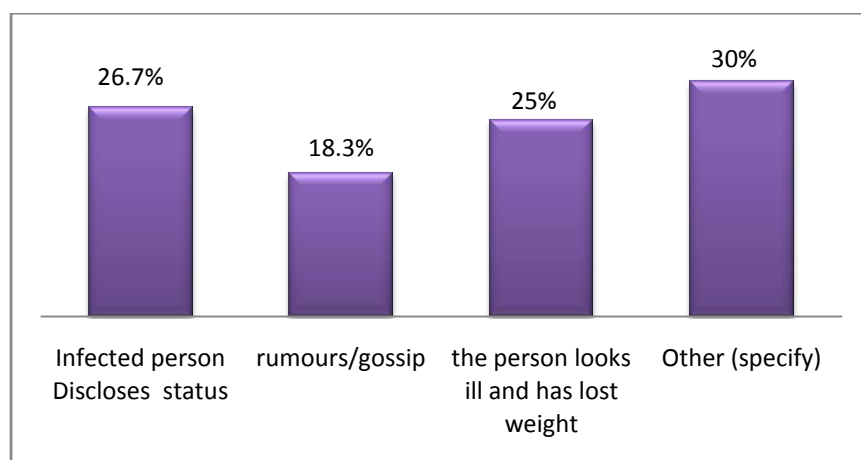


Figure 8

The question required to state the primary way people knew if someone had HIV in the congregation. 30 percent indicated that there was no way of knowing if one is HIV positive in the congregation. 26.7 percent said that the infected percent disclosed his/her status. 18.3 percent knew through rumours/gossip and 25 percent knew when the person looks ill and has lost weight.

Sharing Test Results

	Number of responses	Percentage
Partner	25	41.7
Parents	11	18.3
Family	14	23.3
Friends	6	10
Pastor	22	36.7
Church members	7	11.7
Other	6	10

Table 4.6. Percentages do not add up to 100 percent because of multiple responses

Respondents were asked with whom they would share results if they test positive. 47.1 percent of the respondents would disclose to their partners. 36.7 percent would disclose to the Pastor and only 11.7 percent would disclose to the church members.

4.7 Sources of HIV/AIDS Information (n=60)

Sources of information

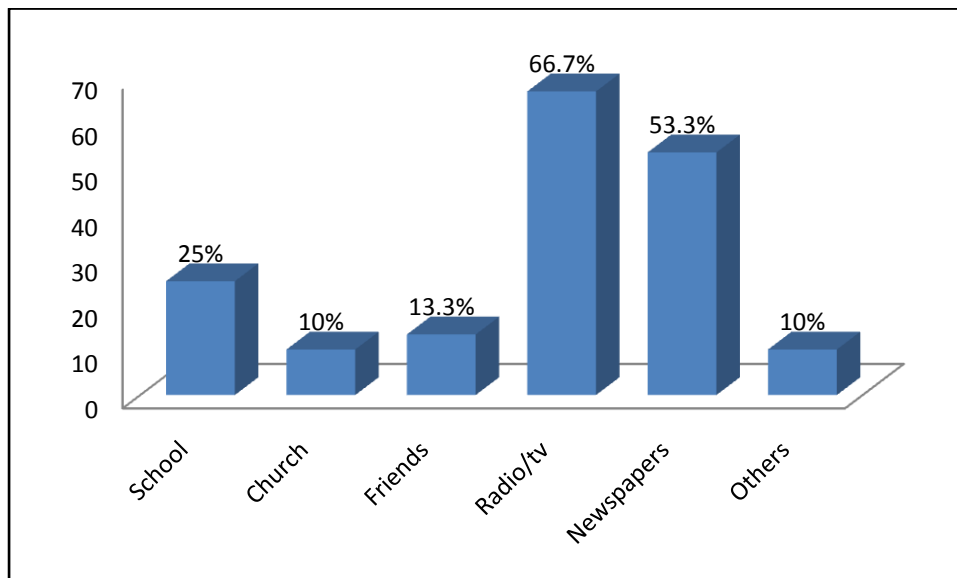


Figure 9: Percentages do not add to a 100 percent because of multiple responses

According to the above findings, the majority of respondents (66.7%) got their information on HIV/AIDS from the radio/TV, followed by newspapers at 53.3 percent. The school came

third at 25 percent and friends came fourth at 13.3 percent. The church constituted of only 10 percent of the responses and another 10 percent mentioned other sources.

Religious Activities for HIV/AIDS Discussions

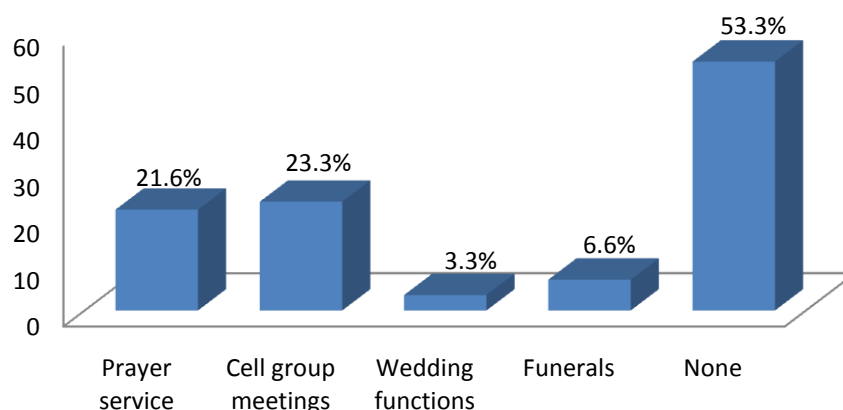


Figure 10: Percentages do not add up to a 100 percent because of multiple responses

Respondents were asked to indicate the religious activities that provided space for HIV/AIDS discussions. According to the findings, 53.3 percent stated that none of the church activities provided an opportunity to talk about HIV/AIDS. Cell group meetings were mentioned by 23.3 percent followed by prayer service at 21.6 percent. 6.6 percent stated that HIV/AIDS is mentioned at funerals, while only 3.3 percent mentioned weddings.

Frequency of HIV/AIDS Discussions

Source	Number of responses	Percentage
Once a week	2	3.3
Once a month	3	5
Less than once a month	7	11.7
Rarely	18	30
Never talked about	30	50

Table 4.7

This question seeks to establish how frequently issues related to HIV/AIDS were addressed. Respondents were asked to rate on the scale of frequency as follows; once a week, once a month, less than once a month, rarely to never talked about. 50 percent revealed that there

was not a single moment when HIV/AIDS issues were discussed in the church. 30 percent stated that the issue was rarely discussed. 11.7 percent recalled that there were discussions around the facts of HIV/AIDS less than once a month while 5 percent of respondents indicated that HIV/AIDS issues were mentioned in their congregation once a month. 3.3 percent stated that HIV and AIDS were mentioned once a week.

Dissemination of HIV/AIDS Information

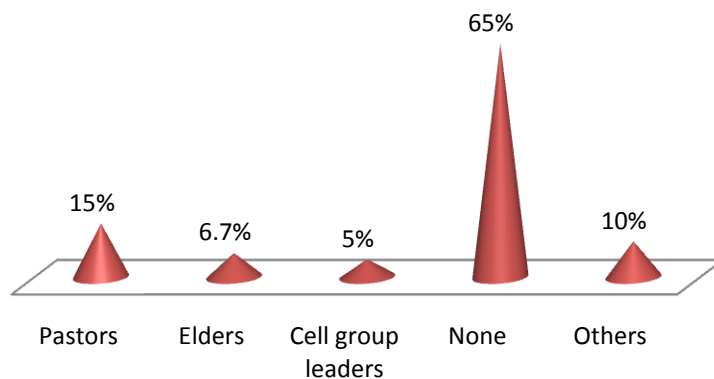


Figure 11: Percentages do not add up to a 100 percent because of multiple responses

Respondents were asked to list the different groups of people within the church who were involved in dissemination of HIV/AIDS information. 65 percent stated that none of the listed group was involved in the latter activity. On the contrary 15 percent recalled that pastors were involved, while 10 stated that other groups not mentioned play a part in disseminating the information. A small proportion of the respondents (6.7 percent) recalled the church elders as playing a part while 5 percent mentioned the cell group leaders.

4.8 Discussion of Findings

Objective 1: to establish the level of HIV/AIDS knowledge of congregants in the church

As the findings indicate, respondents in this study have high levels of knowledge on basic information on HIV/AIDS. A study by the Ministry of Health and Social Services (2007) established that general awareness of HIV/AIDS is relatively high in Namibia, for example, among young people ages 15-24, 82 percent of young women and 87 percent of young men knew that a healthy looking person could be infected with HIV. The high levels of knowledge may be attributed to the various enlightenment programmes in the electronic media in educating people about HIV/AIDS. Respondents are knowledgeable about the methods of transmission which include sexual contact (91.7%), use of contaminated needles/blades (95%), and mother to child through breast milk (75%). It is interesting to note that despite the fact that 91.7 percent knew that sexual contact is the primary means of HIV transmission, 21.7 percent disagreed with the statement that people can reduce their chances of getting HIV by having a monogamous sexual relationship with an HIV-negative partner and while 16.7 percent do not know. However, the data revealed a lack of in-depth knowledge as 25 percent of the respondents indicated that HIV and AIDS are one and the same. This signifies a lack of knowledge on disease progression. Respondents do not have adequate knowledge on the role of ARVs. 23.3 percent indicated as false the statement that ARVs reduce the amount of HIV in the body of an infected person. The high percentage of respondents that are unfamiliar with this aspect indicates that increased attention is needed in educating congregants on antiretroviral treatment. This lack of in-depth knowledge may perpetuate the misconceptions associated with the disease.

Objective 2: to establish the relationship between knowledge and personal stigma

The findings of the study established that generally people are aware how HIV/AIDS is transmitted. This somehow reduces personal stigma, but the increase in knowledge does not necessarily translate to the decrease in stigma. Therefore respondents' beliefs, values and perceptions were in some cases inconsistent with responses provided to test their level of HIV knowledge.

The findings of the study established that generally people were aware that casual contact does not result in transmission. They were aware that sexual contact is the main method of transmission yet 43.3% still had reservations of using the same utensils with PLHA. 51.7% percent had fears of being exposed to the sweat of PLHA. The study shows that a significant minority (21.7%) held fears of transmission through the use of the same toilet with someone who is HIV positive. This is instrumental stigma which arises from the perception that interacting with PLHA poses a direct threat to one's own physical well-being. A person might 'know' how HIV is transmitted and therefore be aware that one cannot become infected via casual contact, but might nevertheless refrain from using the same utensils with PLHA. According to Stein (2003), people may doubt, disregard or disagree with public health information regarding low-risk or non-risk contacts provided to them by public health professionals. This is not to suggest that HIV/AIDS education does not play an important role in decreasing stigma, but that knowledge alone is insufficient to eliminate 'false' beliefs regarding transmission or, for that matter, to eradicate stigma. This goes on to show that in some cases knowledge does not translate to the right actions or attitudes that reduce stigma.

The relationship between knowledge and values (shame, blame, judgment) is that when knowledge increases, stigmatizing values decrease. But at a closer look, there are some respondents who exhibit high stigmatizing values such as the belief that HIV is a punishment (61.7%), PLHA are cursed (45%) and that PLHA have not followed the word of God (58.3%). These perceptions defeat the whole purpose of having high levels of knowledge on HIV/AIDS. These findings are also consistent with Zou et al (2009) who state that religious beliefs about HIV are strongly associated with shame stigma and that religion can be a significant source of negative perceptions about HIV and PLHA. Hence knowledge of HIV does not contribute significantly to a decrease in stigmatizing values.

Although people with increased knowledge are more likely to disclose their status, these findings imply that there are other factors that contribute to willingness to disclose other than knowledge that have a more positive impact. Disclosure of HIV status to pastors or to other members of the religious community can facilitate emotional healing and support, and religion can provide mechanisms for coping and hoping (Zoe, et al 2009). In the study the forum to disclose is non-existence as indicated by 50 percent of the respondents and 33.3 percent who were not sure about such a forum. In addition, disclosure is unlikely to occur in

an environment that is hostile to PLHA regardless of the high levels of HIV/AIDS knowledge the people might have.

Objective 3: to explore enacted HIV stigma in the Church

Objective 3 seeks to establish the existence of enacted stigma at the Christ Embassy Church. Enacted stigma refers to the discrimination and violation of human rights that PLHA experience (Morris, 2003). These indicators reflect the extent of differential treatment of PLHA. It seems to include only those activities which are deemed to be unnecessarily prejudicial. According to Nyblade and Ogden (2005) the enactment of stigma through discriminatory practices includes physical isolation, social isolation; verbal abuse; and institutional discrimination. It might result in loss of friendship, gossip, keeping distance of PLHA or loss of respect of PLHA.

According to the findings, significantly low levels of discriminatory practices were noted. Respondents were asked to report on the practices that they perceive PLHA were forced to deal with in their church. Only 11.7 percent accounted for gossip, while none of the respondents knew of anyone that has been teased because of HIV status. When the respondents were asked if they knew of anyone who had been excluded from participating fully in some church activities because they are HIV positive, 81.7 percent were not aware, only 3.3 percent indicated that such exclusions took place. 13.3 percent indicated that HIV testing is a requirement to marry in the church. Such low reported responses on exclusions are more likely to be reported in situations with high levels of silence on HIV/AIDS issues. PLHA might opt to withdraw from social situations in which stigma may be apparent in order to avoid rejection and blame for their HIV status. Under such circumstances, it becomes difficult to get an accurate assessment of the existence of actual experiences of stigma and discrimination.

Objective 4: to explore causes of HIV-stigma and discrimination in the Church

The findings show that HIV stigma and discrimination in the church is compounded by a number of factors stated below:

Stigma and discrimination can be perpetuated by lack of information. The results of the survey indicated the electronic media (radio/TV) and the print media (newspapers) as the main means of information on HIV/AIDS. Only 10 percent of the respondents indicated the Church as a source of information on HIV and AIDS. 65 percent of the respondents stated that none of the listed groups which included pastors, cell leaders and elders are involved in disseminating information on HIV/AIDS. Therefore the findings of the survey established that dissemination of HIV/AIDS information in the church is lacking. The lack of information gives rise to an environment where myths and stereotypes that surround the disease flourish and in turn, incite irrational fears and anxieties linked to association and contact with people who are or thought to be infected (MIAA, 2006).

Stigma feeds on silence and denial. Paterson (undated) argues that ending stigma demands that the Church shatters the conspiracy of silence and admits to the presence of AIDS in its midst. With 50 percent of the congregants stating that HIV/AIDS is never mentioned in the church, the study established that the issue is not discussed adequately within the Christ Embassy Church. The church has not done much to create a forum for open discussions on HIV/AIDS, thus perpetuating the culture of silence. The reason behind this silence, Xapile (2009) states that the majority of members in faith-based organizations still lack the knowledge, experience and practical skills needed for intervention. According to UNAIDS (2009), institutions and communities may fear the stigma that will fall on them if members are found to be carrying a stigmatized condition.

The secrecy surrounding disclosure of HIV infection is one factor that fuel HIV/AIDS stigma. Respondents were generally unaware of people living with the virus in their congregation. 48.3 percent were not sure, while 26.7 percent did not know of anyone living openly with HIV in the Church. This indicates that disclosure of HIV testing is very low. The lack of a forum for disclosure gives evidence of lack of openness and secrecy surrounding HIV and AIDS in the Church. According to the findings the Church has not provided an opportunity for PLHA to disclose their status. As a result most congregants are not aware of anyone living openly with HIV/AIDS in the congregation. People suspect HIV when one looks ill and when outward manifestations of the illness such as weight loss start to show. In other words, there is no way of knowing until those who are infected are at a stage where the disease has progressed into AIDS and symptoms can no longer be hidden.

Disclosure of HIV-status to pastors or other members of the religious community can facilitate emotional healing and support, and religion can provide mechanisms for coping and hoping (Zou et al, 2009). On the contrary, a majority of respondents in this study would rather share their test results with their partners (41.7%) while 36.7 would share with the Pastor, if they test positive. A low percentage of 11.7 percent would disclose to the religious community. PLHA would rather suffer in silence than seek pastoral assistance or support from other church members. Fears of stigma represent an impediment to disclosure by PLHA of their serostatus to others, including sexual partners and church members which can interfere with effective risk reduction (Stein, 2003). Such reservations are expected in a community where a culture of shame, blame and judgment prevails. Some people might also decide not to disclose so as to avoid ostracization. According to UNAIDS (2005), this creates a huge problem for individuals, for whom the disclosure of stigmatizing information in an unsympathetic, stigmatizing environment can be a fearsome and risky undertaking. Therefore, at Christ Embassy, the whole issue is shrouded in secrecy which can exacerbate the fears associated with the disease.

HIV/AIDS is seen as a result of disobedience and failure to adhere to religious teachings regarding sexual relations (Kafuko, 2009). In this study, there was a clear manifestation of judgmentalism that prevailed. Many people believed that PLHA were responsible for their predicament. There was general perception that HIV is a punishment from God, and that PLHA have not followed the Word of God or cursed. Such perceptions place the church on the path of judgmentalism thereby nurturing stigma and discrimination. Zou et al. (2009) are of the opinion that beliefs such as these have likely contributed to the discrimination that PLHA have reported to have experienced in church settings.

The study recorded significant percentages of the existence of shame stigma among the respondents. Hence 38.3 percent would be ashamed if they test HIV positive, 28.3 percent would be ashamed to have a family member who is HIV positive. 31.7 percent are of the opinion that people with HIV should feel ashamed of themselves. This implies that respondents would hide their HIV status or that of those close to them. They may provide alternate explanations of the nature of an illness if they fall sick. According to (MIAA, 2006), there is a popular opinion that when people know that one is infected and is living with HIV within the congregation, the perceptions, comments and reactions of the fellow congregants play a role in fuelling stigma and the shame associated with the disease.

The association of HIV with morality instigates stigma. The understanding that HIV is transmitted mostly through sexual intercourse fuels the belief that a person contracts HIV because of his/her 'unacceptable' and 'immoral' sexual behaviour. People who get HIV are generally assumed to have 'misbehaved', to have engaged in inappropriate behaviour, and therefore to be deviant because they have not upheld societal norms, and in particular God's teachings (Banteyerga et al, 2003). The association of HIV with immorality is reflected in 28.3 percent of the respondents who agree to the statement that PLHA are promiscuous. This may be attributed to religious teachings which often contribute to the culture of 'blaming'. The latter may be a reasonable explanation why 43.3 percent apportion blame to those who are infected. By blaming individuals or groups, the Church can excuse itself the responsibility of caring for those who are infected.

Contagious diseases such as HIV are subject to the aesthetic factor of stigma. Several studies have established that the basis of HIV/AIDS-related stigma in Africa is fear of contagion, particularly through casual contact, and thus it is powered by inaccurate understandings of HIV transmission. Casual contact fears are deeply rooted, even among people who presumably know better (GAIA, 2005). A significant number of respondents reported fears of being infected through ordinary body fluids, drinking from the same communion cup or using the same utensils with PLHA.

Chapter 5: Conclusion and recommendations

5.1 Conclusion

The findings of the study highlighted a number of attitudes, practices and beliefs about HIV/AIDS that were perceived to contribute to stigmatization and discrimination in the Church. Although some factors that have fuelled HIV stigma are consistent across different contexts, the findings of this study suggested that HIV/AIDS stigma in the church is deeply rooted in religious beliefs and practices. HIV-related stigma and discrimination presents a challenge to Christian Theology particularly as the result of the perception of AIDS as a disease caused by immorality and sin. The widely held assumption that HIV is always contracted as the result of 'sinful' sexual relations has been reinstated by those who regard PLHA as promiscuous. Such beliefs are consistent with the religious versions of the punishment theory of disease, which then justifies illness as divine punishment inflicted on human beings to punish them for an offence. PLHA suffer in silence, they do not disclose or seek support from the Church either due to the fact that they have no forum to do so or they fear to face the shame associated with such a highly stigmatized disease. So despite the relatively high knowledge of HIV/AIDS, attitudes, beliefs and practices that fuel stigma are evident in the Christ Embassy Church. The study also established that generally, the correlation between increased HIV/AIDS knowledge and decreased stigma does exist, but may also be accounted for in a number of ways which are beyond the scope of the current study.

5.2 Recommendations

The following recommendations have been made based on the findings of this study.

- The study encourages disclosure as one strategy to diffuse AIDS stigma in the Church. PLHA should be encouraged to give testimonies and share their experiences in dealing with the disease during church services and other religious gatherings. Often disclosure and open communication can reduce the associated shame that accompanies the disease and helps others come to terms with the risk of HIV/AIDS. Disclosure increases visibility of PLHA resulting in acceptance and support for those who are infected.

- Pastors should speak openly, compassionately and non-judgmentally about HIV/AIDS, thereby dispelling the culture of silence and acknowledging the presence of the disease in the Church. This creates a conducive environment and a culture of concern and care for PLHA. The influence of religious leaders cannot be underestimated as they command moral authority and can therefore act as agents of change in reducing HIV stigma.
- The study has established that although congregants are knowledgeable about HIV/AIDS, they still exhibit stigmatizing perceptions, beliefs and attitudes. Congregants should be sensitized on HIV-stigma and discrimination and the consequences it has on PLHA. Some may not be aware that certain beliefs are stigmatizing viz-a-vis the belief that 'HIV is a punishment from God'. There is a need to create awareness and recognition of the existence of stigma, different forms of stigma and how it manifests. People should be made aware of the drivers of stigma as established by the findings of the current study and the benefits of reducing it. Sensitization can be done through guest speakers from local Faith-based Organizations (FBOs) that deal with AIDS.
- The study recommends the provision of Information, Education and Communication (IEC) material in raising awareness among congregants about HIV/AIDS stigma and discrimination. Information needs to focus at bringing changes in values, attitudes and perceptions. The provision of accurate and timely information to dispel the doubts and fears, myths and misconceptions associated with the disease will help to reduce stigma. Information in local languages should also be made available. Christ Embassy Church can liaise with UNAIDS and other AIDS service organizations which provide free publications in order to make the literature readily available on a regular basis.
- Home visits by the pastors/congregants of AIDS patients may be assisted with care and financial support. Home based support network through churches is an avenue for reducing stigma and promoting understanding. As more people have direct contact with friends and family members who have died or are ill with AIDS, a greater openness should ensure.

5.3 Limitations of research

The limitation of this study is that it was based only on congregants of the Christ Embassy Church who belong to a cell group. Findings cannot be generalized to all members of all Christian faith communities. A larger sample conducted on a wider scale which includes the mainline churches, and/or evangelical churches, could have revealed diverse views, values and perceptions that are held by members of different churches.

The discrepancy to answers on certain practices, for instance whether there was a forum for disclosure in the Church, is an indication that some questions have not been honestly answered. The reason for this could be that respondents might know what was looked for and provided answers that were not what they believed or practiced.

5.4 Areas of further research

The research identified the following areas for further research:

- Explorative study to establish the experiences of stigma and discrimination faced by PLHA in the faith communities;
- A qualitative study which seeks to probe certain beliefs which are stigmatizing in order to establish why people hold on to those beliefs;
- A comparative study on HIV stigma and discrimination in Christian and Muslim faith communities in Namibia.

References

Babbie, E. (2005). The Basics of Social Research. 3rd ed. Canada: Thomson Wadsworth

Banteyerga, H; Kidanu, A; Nyblade, L; MacQuarrie, K and Pande, R (2003). Yichalaliko: Exploring HIV and AIDS Stigma and Related Discrimination in Ethiopia: Causes, Manifestations, Consequences and Coping Mechanisms. Addis Ababa: Miz-Hasab Research Center

Bos A; Schaalm H; Mbwapbo J (2004). "Reducing AIDS-Related Stigma in Developing Countries: the Importance of Theory-and Evidence-based Interventions." Sexual Health Exchange 2004-2. KIT

Brooks RA; Etzel MA; Hinojos E; Henry CL; Perez (2005). "Preventing HIV Among Latino and American African Gay and Bisexual Men in a Context of HIV-Related Stigma, Discrimination, and Homophobia: Perspectives of Providers." AIDS Patient Care STDs. 2005 November; 19 (11): 737-744

Catholic Bishops of Uganda. (1989). The AIDS Epidemic: Message of the Catholic Bishops of Uganda. Kisubi: Marianum Press

Carter, M (2008). HIV & Stigma. London: NAM

Chitando, E. (2007). Living with Hope: African Churches and HIV/AIDS 1. Geneva: World Council of Churches

Christensen, LB (2007). Experimental Methodology. (Tenth Edition). Boston: Allyn and Bacon

Corrigan P; Watson A; Gracia G; Slopen N; Rasinski K; Hall L. Newspaper Stories as Measures of Structural Stigma. May 2005 Vol. 56 No:5. <http://ps.psychiatryonline.org>. accessed on 13 November 2010

DFID/Futures Group (2005). HIV and AIDS: Stigma and Faith-based Organizations: A Review. Bath, London: DFID

Fife B and Wright E (2000). The Dimensionality of Stigma: A Comparison of its Impact on the Self of Persons with HIV/AIDS and Cancer. *Journal of Health and Social Behaviour*. Vol. 41(1) p. 50-67

Genberg, B L, Chingona A, Sendah M, Chariyalertsak S, Konda KA and Celentano D. (2007). *Assessing HIV/AIDS Stigma and Discrimination in Developing Countries*. New York: Springer Science and Business Media

Genrich, G and Brathwaite B. (2005). "Response of Religious Groups to HIV/AIDS as a Sexually Transmitted Infection in Trinidad. Published in *BMC Public Health*, 2005;5:121

Greif G and Porembski E. (1988). AIDS and Significant Others: Findings from a Preliminary Exploration of Needs. *Health and Social Work*, 13.259-265

Global AIDS Interfaith Alliance (GAIA) 2005. *A Call for Community: Two Papers on HIV and AIDS Related Stigma in Africa*. San Francisco, California: GAIA

Jackson, H. (2002). *AIDS Africa: Continent in Crisis*. Harare: SAFAIDS.

Herek GM, Capitano JP (1999). "AIDS Stigma and Sexual Prejudice Am *Behavioural Scientist*. 1999;42 (7):1126-43

Herek, G & Capitano J.R. (1998) Symbolic Prejudice of Fear of Infection? "A Functional Analysis of AIDS-related Stigma Among Heterosexual Adults." *Basic and Applied Social Psychology* 20 (3) 230-241

Herek, G & Glunt, E. (1988). "An Epidemic of Stigma, Public Reactions to AIDS." *American Psychologist* 43 (11): 886-891

Huggins, J; Baggaley, R and Nunn, M (2004). God's Children are Dying of AIDS: Interfaith Dialogue and HIV. Christian AID

International Center for Research on Women (ICRW) 2010. Scaling Up the Response to HIV Stigma and Discrimination. London: ICWR and London School of Hygiene and Tropical Medicine

ICRW (2003). Disentangling HIV and AIDS Stigma in Ethiopia, Tanzania and Zambia. www.icrw.org/docs. Accessed 25 November 2010

ICRW (2002). Understanding HIV-related stigma and resulting discrimination in Sub-Saharan Africa: Emerging themes from early data collection in Ethiopia, Tanzania and Zambia. http://www.icrw.org/docs/Stigma_ResearchUpdate_062502. Accessed 25 November 2010

The International Community of Women Living with HIV/AIDS (ICW) 2009. The Forced and Coerced Sterilization of HIV Positive Women in Namibia. Windhoek: ICW

ICW (2006). Trialling of the Monitoring Tool fulfilling reproductive rights for women affected by HIV. A tool for monitoring achievement of Millennium Development in Namibia. Windhoek: ICW

Kafuko, A (2009). A Study on Knowledge, Attitudes and Practices Related to HIV/AIDS Stigma and Discrimination Among People Living with HIV, Caretakers of HIV+ Children and Religious Leaders. Johns Hopkins Center for Communications Programmes & Uganda AIDS Commission

Kopelman, LM. Chapter 1. If HIV/AIDS is a punishment, who is bad? In Van Niekerk, AA & Kopelman, LM. eds. (2005) Ethics and AIDS in Africa: the Challenge to Our Thinking. Cape Town: David Philip

Latino Commission on AIDS (2006). Reducing the Stigma of HIV/AIDS: Through Understanding, Compassion and Action. New York: Latino Commission on AIDS

Malawi Interfaith AIDS Association (MIAA) 2006. HIV and AIDS Related Stigma and Discrimination within the Faith Community in Malawi: An Operational Research. Lilongwe: MIAA

Mansergh, G; Marks, G; Simoni J. (1995). Self-disclosure of HIV Infection Among Men Who Vary in Time Since Seropositive Diagnosis and Symptomatic Status. AIDS. 1995 June; 9 (6): 639-644

Masindi, N. (2004) Siyamk'ela: linking research and action for stigma reduction in South Africa. (Article in Sexual Health Exchange. 2004-2. Amsterdam: KIT)

Maughan-Brown, B. (2004). Measuring HIV/AIDS Stigma. CSSR Working Paper No.74. Centre for Social Science Research, University of Cape Town

Ministry of Health and Social Services, Government of Namibia (2005). Report of the 2004 National HIV Sentinel Survey. Windhoek: MOHSS

Morrison K. 2006. Breaking the Cycle: Stigma, Discrimination, Internal Stigma, and HIV. Washington, DC: The Policy Project

Morris, S (2003). The Enigma of HIV/AIDS-related Stigma: A Theoretical Exploration of HIV/AIDS-related Stigma in sub-Saharan Africa.

The Namibian, May 28 2010. p.1-2

Nyblade, L and MacQuarrie K. 2006. Can We Measure HIV/AIDS Related Stigma and Discrimination? Current Knowledge about Quantifying Stigma in Developing Countries. Washington, DC: USAID

Nyblade, L and Carr D. (undated) Towards a Stronger Response to HIV and AIDS: Challenging Stigma. DFID

Ogden, J and Nyblade, L. (2005). Common at its Core: HIV-Related Stigma Across Contexts. International Center for Research on Women

Pan African Christian AIDS Network (PACANet) 2003. Situation Analysis of the Church Response to HIV/AIDS in Namibia: Final Report. Windhoek: PACANet.

Parker, R and Aggleton, P (2003). HIV and AIDS related Stigma and Discrimination: a Conceptual Framework and Implications for Action. Social Science and medicine, 57. p15-24

Parker, R and Aggleton, P (2002). A Conceptual Framework and Basis for Action: HIV/AIDS Stigma and Discrimination. Geneva: UNAIDS

Parker, R; Aggleton, P; Attawel, K; Pulerwitz, J and Brown, L (2002). HIV/AIDS Related Stigma and Discrimination: A Conceptual Framework and an Agenda for Action. New York: The Population Council

Parry, S. (2008). Beacons of Hope HIV Competent Churches: A Framework for Action. Geneva: World Council of Churches

Paterson (undated) Church, AIDS and Stigma. Unpublished.

The Policy Project (2003). Literature Review: Siyam'kela Research Study. South Africa

The Policy Project (2003). Siyam'kela: Measuring HIV/AIDS Related Stigma-Tackling HIV/AIDS Stigma: Guidelines for Faith-based Organizations. Cape Town: Policy Project

The Policy Project (2003). Tackling HIV/AIDS Stigma: Guidelines for Faith Based Organizations. USAID/Policy Project, Centre for the Study of AIDS (University of Pretoria) and the National Department of Health (South Africa)

Royal Tropical Institute (KIT) 2004. Faith-based Organizations and HIV/AIDS Prevention and Impact Mitigation in Africa. Bulletin 361. Amsterdam: KIT Publishers

Sarantakos, S. (2002). Social Research. New York: Palgrave.

Speicher, S and Wilson, J. (2007). Exploring Solutions: How to Talk About HIV Prevention in the Church. Geneva: Ecumenical Advocacy Alliance.

Stein J. (2003) HIV/AIDS Stigma: The Latest Dirty Secret. CSSR Working Paper No.46. AIDS and Society Research Unit. University of Cape Town

UNAIDS (2007) Practical Guidelines for Intensifying HIV Prevention: Towards Universal Access. UNAIDS, Geneva

UNAIDS (2007). AIDS Epidemic Update: December 2007. Geneva: UNAIDS

UNAIDS. 2006 Report on the Global AIDS Epidemic, Joint United Nations Program on HIV and AIDS, Geneva

UNAIDS (2005). A Report of a Theological Workshop Focusing on HIV- and AIDS-related stigma. 8th-11th December. Windhoek: UNAIDS

UNAIDS (2003). Fact Sheet: Stigma and Discrimination. Geneva: Joint United Nations Programme on HIV/AIDS

UNAIDS (2002). HIV/AIDS Stigma and Discrimination: A Conceptual Framework and Basis for Action. Geneva: UNAIDS

UNAIDS (2001). Uganda: HIV and AIDS-related Discrimination, Stigmatization and Denial. Geneva: UNAIDS

UNAIDS (2000). HIV and AIDS-related Stigmatization, Discrimination and Denial: form, context and determinants: Research studies from Uganda and India. Geneva: UNAIDS

UNESCO (undated). Easy Guide to Undertake Socio-Cultural Research. UNESCO

United Nations (2001) Declaration of Commitment on HIV/AIDS. United Nations General Assembly Special Session on HIV/AIDS, 25-27 June 2001

Van Niekerk, AA. (Undated). Individual Versus “Group” Rights in the HIV/AIDS Debate: Does More Bad News Make Any Difference? (Unpublished lecture)

Van Wyngaard, A (2005). “Towards a Theology of HIV/AIDS” Paper presented to the General Assembly of the Reformed Ecumenical Council held in Utrecht, Netherlands from 12-25 July 2005. Department of Religious Studies: University of Pretoria

Wolfe W; Weiser S; Bangsberg d; Thior I; Makhema J; Dickinson D (2006). Effects of HIV-Related Stigma Among an Early Sample of Patients Receiving Antiretroviral Therapy in Botswana. *AIDS Care*, 18 (8), 931-933

Xapile, S. (2009). The Role of Faith-based Organizations Prevention, Care and Support for People Living with HIV/AIDS. Stellenbosch University.

Zou, J; Yamanaka, Y; John, M; Watt, M; Ostermann, J; Thielman, N (2009). “Religion and HIV in Tanzania: Influence of Religious Beliefs on HIV Stigma, Disclosure, and Treatment Attitudes.” Article in *BMC Public Health* 2009, 9:75.
<http://www.biomedcentral.com/1471-2458/9/75> Accessed on 28 October 2010

QUESTIONNAIRE

(Please answer questions by placing an 'X' in the appropriate box. Do not write your name)

(PLHA – People Living with HIV and AIDS)

T = True

F = False

DK = Don't Know

Section A: Socio-Demographic Data

1. Age: ☐ 21-30 ☐ 31-40 ☐ 41-50 ☐ 51 and above
2. Gender: ☐ Female ☐ Male
3. Marital status: ☐ Single ☐ Married ☐ Divorced ☐ Separated
☐ Widowed
4. Education level: ☐ Primary level ☐ Secondary level ☐ Tertiary level
☐ University

Section B: Knowledge about HIV and AIDS

5. There is no difference between HIV and AIDS ☐ T ☐ F ☐ DK
6. A person can have HIV without becoming ill with AIDS ☐ T ☐ F ☐ DK
7. People who look healthy are not infected with HIV ☐ T ☐ F ☐ DK
8. Sexual contact is the primary means of HIV transmission ☐ T ☐ F ☐ DK
9. A person can get HIV by being bitten by a mosquito or any insect ☐ T ☐ F ☐ DK
10. HIV can be transmitted from mother to child through breast-feeding ☐ T ☐ F ☐ DK
11. AIDS can be spread through the use of contaminated needles/blades ☐ T ☐ F ☐ DK
12. A pregnant woman infected with HIV can decrease the chance of transmitting the virus to the unborn child by taking antiretroviral drug ☐ T ☐ F ☐ DK
13. People can reduce their chances of getting HIV by having a monogamous sexual relationship with an HIV-negative partner ☐ T ☐ F ☐ DK
14. Antiretroviral treatment reduces the amount of HIV in the person's body ☐ T ☐ F ☐ DK
15. An HIV test can remain negative for a few months after someone is infected ☐ T ☐ F ☐ DK

Section C: Fears of casual contact

Do you have fear of becoming infected?

16. If you share the same utensils with someone who is HIV positive?

☐ Yes ☐ No

17. If you drink from the same communion cup with an HIV-infected person?

☐ Yes ☐ No

18. If you shake hands with someone who is HIV positive?

☐ Yes ☐ No

19. If you sit next to someone who is showing signs of AIDS?

☐ Yes ☐ No

20. If you use the same toilet with someone who is HIV positive?

☐ Yes ☐ No

21. If you are baptized in the same water with PLHA ☐ Yes ☐ No

22. If you touch a PLHA ☐ Yes ☐ No

23. If you are exposed to the sweat of a PLHA ☐ Yes ☐ No

24. Is it safe for a Sunday school teacher who is HIV positive to work with children?

☐ Yes ☐ No

Section D: Values (shame, blame, judgment)

Do you agree or disagree with the following statement?

25. HIV is a punishment from God ☐ Agree ☐ Disagree

26. PLHA have not followed the Word of God ☐ Agree ☐ Disagree

27. PLHA are cursed ☐ Agree ☐ Disagree

28. People with HIV are promiscuous ☐ Agree ☐ Disagree

29. People with HIV lose respect in the congregation ☐ Agree ☐ Disagree

30. PLHA do not deserve any support ☐ Agree ☐ Disagree

31. People with HIV should feel ashamed of themselves ☐ Agree ☐ Disagree

32. I would feel ashamed if I was HIV positive ☐ Agree ☐ Disagree

33. People with HIV have themselves to blame ☐ Agree ☐ Disagree

34. If you have a family member with HIV, would you feel ashamed?
☐ Agree ☐ Disagree

Section E: Enacted Stigma

Do you know someone in the church who has had the following happen to him/her because of HIV or AIDS?

35. Gossiped about ☐ Yes ☐ No ☐ Not Sure
36. Teased or sworn at ☐ Yes ☐ No ☐ Not Sure
37. Lost respect/standing within the church ☐ Yes ☐ No
☐ Not Sure
38. No longer visited, or visited less frequently by members of the church
☐ Yes ☐ No ☐ Not Sure
39. Excluded from participating fully in some church activities
☐ Yes ☐ No ☐ Not Sure
40. Isolated within the church ☐ Yes ☐ No ☐ Not Sure
41. Lost friends within the church ☐ Yes ☐ No ☐ Not Sure
42. Required to take HIV testing in order to marry in the church
☐ Yes ☐ No ☐ Not Sure

Section F: Disclosure

43. In your congregation, are there people who are living openly with HIV and AIDS?
☐ Yes ☐ No ☐ Not Sure
44. Are people in your congregation given a forum to disclose their HIV status?
☐ Yes ☐ No ☐ Not Sure
45. What is the primary way people know if someone has HIV in your congregation?
☐ the infected persons discloses his/her status
☐ rumours/gossip
☐ the person looks ill and has lost weight ☐ Other (specify)
46. If a family member has HIV, would you keep it a secret?
☐ Yes ☐ No
47. If you test positive, would you share your results with anyone?
☐ Yes ☐ No
48. If you test positive with whom would you share the test result? (you may tick more than one box)
☐ Partner ☐ Parents ☐ Family ☐ Friends ☐ Pastor ☐ Church members ☐ Other (specify)

Section G: Sources of HIV/AIDS information

49. What are the main sources of information on HIV and AIDS in your community?

- ☐ School ☐ Friends ☐ Newspapers
☐ Church ☐ Radio/tv ☐ Others

50. What are the religious activities that provide space for HIV and AIDS discussions?

- ☐ Prayer service ☐ Cell group meetings
☐ Wedding functions ☐ Funerals ☐ None

51. How frequently are issues related to HIV and AIDS addressed during church functions?

- ☐ Once a week ☐ Once a month ☐ Less than once a month
☐ Rarely ☐ Never talked about

52. List the different groups of people within the church who are involved in dissemination of HIV and AIDS information

- ☐ Pastor(s) ☐ Elders ☐ Cell group leaders
☐ None ☐ Others

THANK YOU FOR YOUR COOPERATION



UNIVERSITEIT•STELLENBOSCH•UNIVERSITY
jou kennisvennoot • your knowledge partner

STELLENBOSCH UNIVERSITY CONSENT TO PARTICIPATE IN RESEARCH

TITLE OF STUDY: Factors that Contribute to HIV-related Stigma and Discrimination in Faith Communities – With Specific Reference to the Windhoek Christ Embassy Church

You are asked to participate in a research study conducted by Nomusa Senzanje (BA English and Communication [University of Zimbabwe]; National Diploma in Library and Information Sciences [Harare Polytechnic]; Postgraduate Diploma in HIV/AIDS Management [Stellenbosch]). She is currently studying at the Africa Centre of HIV/AIDS Management – Department of Economic Management at Stellenbosch University.

The results will contribute to a mini-thesis to be submitted in partial fulfillment of the Master of Philosophy degree in HIV/AIDS Management.

You were selected as a possible participant in this study because you are a member of the Christ Embassy Church who belong to a cell group. You also fall within the age range of 21 years and above and you are **sufficiently fluent in English to complete the survey instrument.**

1. PURPOSE OF THE STUDY

To establish the underlying causes of HIV-related stigma and discrimination within faith communities – with specific reference to the Windhoek Christ Embassy Church.

2. PROCEDURES

If you volunteer to participate in this study, we would ask you to do the following things:

- a. Read the consent form and ask for any ambiguities;
- b. Sign the consent form;
- c. Read the questionnaire and ask for clarification to any questions to the researcher that may seem unclear;
- d. Complete the questionnaire individually on-site, during the cell group meeting;
- e. Return the completed questionnaire to the researcher.

In participating in this study, you are required to respond to the questionnaire, which will take about 30-45 minutes.

3. POTENTIAL RISKS AND DISCOMFORTS

There are no medical risks or discomforts associated with this study.

4. POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

People might not be aware that their attitudes and actions are stigmatizing and discriminatory against HIV positive people. The findings of the study may assist the church to implement effective intervention strategies to mitigate stigma and discrimination, thereby benefiting members of the church especially those living with HIV and AIDS.

5. PAYMENT FOR PARTICIPATION

There will be no financial payment for participation in this study.

6. CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Confidentiality will be maintained by means of keeping all electronic files password protected. The researcher and the supervisor can only access the electronic data files. Hard copies of the completed questionnaires will be kept in a filing cabinet under lock and key.

The names of the participants who filled in the consent forms will not be disclosed in the study findings and will not be linked to the completed questionnaires.

7. PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

8. IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research, please feel free to contact:

- (1) Ms Nomusa Senzanje (Researcher): Tel. no. +264 608064510 of No. 2 Kuiseb Street, 18 Lalapanzi Flats, Eros, Windhoek, Namibia. E-mail: mthethwanomusa@yahoo.co.uk
- (2) Dr Thozamile Qubuda (Supervisor): Tel: +27 21 808 3999; Africa Centre for HIV & AIDS Industrial Psychology, Stellenbosch University, Private Bag X1 Matieland 7602. E-mail: tqubuda@sun.ac.za

9. RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development.

SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE
--

The information above was described to [me/the participant] by **Nomusa Senzanje** in English and I the participant is in command of this language. I/the, participant was given the opportunity to ask questions and these questions were answered to my satisfaction.

I hereby consent voluntarily to participate in this study. I have been given a copy of this form.

Name of Subject/Participant

Signature of Subject/Participant or Legal Representative

Date

SIGNATURE OF INVESTIGATOR

I declare that I explained the information given in this document to _____
[He/she] was encouraged and given ample time to ask me any questions. This conversation was conducted in English and no translator was used.

Signature of Investigator

Date

Africa Centre for HIV & AIDS
Industrial Psychology
Stellenbosch University
Private Bag X1
Matieland 7602

28 July 2010

Dear Ms Nomusa Senzanje

RE: Request for Permission to Conduct Research

This letter serves to inform you that your request to conduct a study concerning factors that contribute to HIV/AIDS related stigma and discrimination in faith communities, with members of the Christ Embassy Church in Windhoek for your *MPhil thesis on HIV/AIDS Management* is hereby granted.

I wish you the best in your studies.


.....
Pastor Drilan Cagnetta
Group Pastor